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Expert Consensus Statement on Breastfeeding and HIV in the United States and Canada

Submitted on Dec 1, 2020

Breastfeeding1, while a multi-layered and morally charged issue, is considered the healthiest option for infant feeding for the general population. Among women and other birthing parents living with HIV, infant-feeding choices are even more complex, and feature unique challenges.

Image

This statement references both "women" and "other birthing parents." Women have historically been left out of HIV programming and funding priorities, contributing to inequitable outcomes. As the authors of this statement ground this work in an expansive view of gender and family building, it remains important to specifically address women. References to "parents" are intended to encompass those who do not identify as women, including trans men and non-binary individuals, as well as the non-birthing members of parenting units.

Breastfeeding is the standard of care in low-resource settings where it has been consistently demonstrated to promote the overall survival and well-being of HIV-exposed infants, with an extremely low risk of HIV transmission when the breastfeeding parent has sustained viral suppression. In the United States, Canada, and other high-resource settings, however, public health guidelines oppose breastfeeding among women living with HIV, primarily out of concern for potential transmission. As a result, there is very limited research on breastfeeding and HIV in these areas and a lack of information and clinical standards for providers to support women living with HIV in their decision-making around infant feeding.

The elimination of any risk of HIV transmission is often the only factor considered in counseling women

about infant-feeding decisions. This ignores challenges related to health disparities and family, cultural, and economic values, as well as the potential benefits and advantages of breastfeeding. Insistence on a “zero-transmission-risk” choice concerning breastfeeding is also at odds with the autonomy of parents living with HIV and their fundamental right to make informed choices about their children’s care without judgment or interference from providers or government.2,3

Increasingly, stakeholders across the HIV community are questioning whether infant-feeding guidelines in the United States and Canada reflect the optimization of risks and benefits for this population. This discourse has evolved out of a long-standing need to acknowledge and respect bodily autonomy (the right for a person to govern what happens to their body without external influence or coercion). Additionally, as Undetectable Equals Untransmittable (U=U) (the fact that a person with a suppressed viral load cannot sexually transmit HIV) has become widely accepted, questions have emerged around its application to other modes of transmission, including breastfeeding and injection drug use.

In October 2020, a multi-disciplinary, multi-sectoral group of 23 experts from the United States and Canada convened to identify and discuss the top priorities to ensure that parents living with HIV are able to make the best infant-feeding decisions for themselves and their babies.

Co-signers to the resulting Consensus Statement assert the need for parents living with HIV to have access to the information, support, and tools necessary to make informed infant-feeding decisions. All endeavors in this field will be strengthened by recognizing the autonomy of women and parents living with HIV and building upon a trust that they will make the best decisions for themselves and their families when equipped with comprehensive information and adequate resources and support. They will also be informed by the fact that this work exists in a context of structural racism, colonization, assimilation, anti-Blackness/anti-Indigenous, gender bias, and economic justice. Successful programming will include women and other birthing parents living with and affected by HIV at every level of development and implementation.

Co-signers further stress the need for programming to advance research, policy, and educational resources for women and other birthing parents living with HIV and those who care for them. All individual and organizational stakeholders working in HIV and intersectional communities including gender justice, women's health, reproductive justice, and others, are invited to sign onto this Consensus Statement calling for stakeholders to:*

- **Recognize, account for, and advocate to change the intersectional conditions** that specifically impact women living with HIV, particularly as they relate to their infant-feeding decisions
- **Understand and respect the fundamental right** of women and other birthing parents to make informed, uncoerced choices about their sexual and reproductive health, contraception, pregnancy, and medical care, and about the care of their children.
- **Develop provider education and tools** to address the complex realities facing parents living with HIV in their infant-feeding decisions and their rights to make informed decisions about the best course of care and treatment for their children
- **Create parent resources and support peer-to-peer systems** to provide parents living with HIV with comprehensive education and support around infant feeding
- **Engage in policy reform** to ensure guidelines reflect the rights of women and other birthing parents to parent their children and best practices; center their intersectional lived experiences and agency; and address the criminalization of women living with HIV, including those who breastfeed
- **Advance research** to understand existing data on HIV and infant feeding and identify and address remaining knowledge gaps

**additional details around recommended actions can be found below*

With widespread endorsement of this consensus statement, the co-signers expect to build significant momentum that will help advance efforts outlined above and improve the landscape for parents living with HIV. We invite you to endorse our statement as an organization and/or individual today!

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Endorsed by (as of January 30, 2024):

Organizations

- The Well Project
- ICW-NA
- Association of Ontario Midwives
- Positive Women's Network - USA
- San Francisco AIDS Foundation
- Positive Pregnancy Program Toronto, Canada
- Prevention Access Campaign
- Peterborough AIDS Resource Network
- GLIDE
- Openly Positive Inc
- CATIE

- Sero Project
- East Bay Getting to Zero
- Compass Family Services
- Older Women Embracing Life
- Homeless Prenatal Program
- National Perinatal HIV Hotline, NCCC
- Y-PEER Asia Pacific Center Bangkok
- Working Group on Disabilities and 2030 Agenda (WG2030)
- National Networks of Y-PEER in Asia Pacific
- National Working Positive Coalition
- The Nevada HIV Modernization Coalition
- Positive People Network, Inc.
- Hyacinth AIDS Foundation
- Cush Health Impact
- Health & Education Alternatives for Teens, SUNY Downstate Health Sciences University
- Transgender Strategy Center
- The Center for HIV Law & Policy (CHLP)
- Christie's Place
- National Aboriginal Council of Midwives
- Lady BurgAndy, Inc.
- Howard Brown Health
- AVAC
- HIVE, San Francisco General Hospital, UCSF
- The Afiya Center
- Black AIDS Institute
- Canadian Positive People Network (CPPN)
- AIDS United
- Treatment Action Group
- HIV Justice Network
- Grupo de Trabajo sobre Tratamientos del VIH (gTt-VIH)
- Equals_Id
- Deirdre Speaks
- AIDS Alabama
- Let's Kick ASS AIDS Survivor Syndrome
- New Community Fellowship Ministries, Inc.
- Blossoming In Red Inc
- Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM)
- Mother and Child Alliance
- HIV Medicine Association (HIVMA)
- Butta's Holistic Services
- ICW Argentina

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Endorse the Consensus Statement

1Throughout this document, the term "breastfeeding" is used with the acknowledgement that there are other terms/practices, such as "chestfeeding," for feeding an infant from one's body.

2Parents have a fundamental right under the United States Constitution to raise their children without state interference. Troxel v. Granville, 530 U.S. 57, 65 (2000) ("The liberty interest of parents in the care, custody, and control of their children is perhaps the oldest of the fundamental liberty interests recognized by this Court.").

3*B. (R.) v. Children's Aid Society of Metropolitan Toronto* [1995] 1 SCR

315: https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/1220/index.do.

Additional Context Around Infant Feeding Among Parents Living with HIV

Infant feeding among women and other birthing parents living with HIV is an issue at which many structural factors converge, providing the community with a tremendous, powerful opportunity to create models that address them as it coalesces a field of study and practice. Briefly, those factors include:

- Structural racism, gender bias, and other traumas that promote and perpetuate the HIV epidemic among Black and Indigenous women and other women of color. Further, regardless of income, Black and Indigenous women are far more likely to die, or have their babies die, during birth or postpartum than other races. These conditions also result in Black and Indigenous women and infants experiencing a greater burden of many health conditions that research has shown may be attenuated by breastfeeding.
- Poverty and access to resources among some parents living with HIV in the United States and Canada. While these are considered high-resource countries, there are many communities that lack access to consistent clean water, reliable public transportation, formula, and healthcare services.
- Biased policing and application of policies that lead to low-income communities, particularly Black and Indigenous communities and other communities of color, being unjustly surveilled. This occurs not just on the streets but in healthcare settings and in relation to the care of their children (e.g., Child Protective Services). HIV status compounds this reality.
- Racism, colonization/assimilation, and xenophobia that may influence the "North/South divide" and the degree to which the scientific community in high-resource settings may value sound research findings from low-resource settings (including sub-Saharan Africa and India) conducted among Black and Indigenous women and women of color.

Priorities and Challenges Affecting Infant Feeding Among Women** Living with HIV

In preparation for the convening that informed this Consensus Statement, the participating experts took part in a survey (n=21) to identify important issues related to infant feeding among women living with HIV. The survey investigated the most important priorities for infant feeding among women living with HIV and the biggest challenges to achieving them. Highlights include:

Top priorities

- Additional research to understand HIV transmission through breast milk among women living with HIV who have sustained viral suppression – 76%
- Increased/improved provider education addressing existing research on breastfeeding among women living with HIV, risks and benefits for women living with HIV and their babies, ethical issues around guidance related to breastfeeding among women living with HIV, and harm reduction strategies – 57%
- Increased/improved education for women living with HIV addressing existing research on

breastfeeding among women living with HIV, risks and benefits for women living with HIV and their babies, ethical issues, harm reduction strategies, and rights of women living with HIV if they choose to breastfeed – 48%

Top challenges

- Disregard for the bodily autonomy and decision-making ability of people living with HIV and parents – 48%
- Inadequate resources for providers to support the infant-feeding decisions of women living with HIV and lack of knowledge around harm reduction strategies – 43%
- Lack of understanding among providers of existing breastfeeding research, its implications, and limitations – 38%
- Criminalization, including HIV criminalization and criminalization of pregnant people, especially Black and Brown parents – 33%

Why is this topic important? (select responses from survey participants)

- "It represents one of the current frontiers of HIV stigma/moral panic, it is a salient example of how compounded biases affect healthcare practice with great potential harms for long-term health and equity, and is a key example of why we must eliminate the maternal-fetal conflict framing of perinatal care and ethics as it incorrectly assumes that healthcare providers take infants' best interests to heart more than their own mothers."
- "I am an HIV-positive woman and mother and I believe that women living with HIV should have access to ALL of the information around breastfeeding as well as self-determination and choice."
- "I have had many [women living with HIV] express interest in breastfeeding and one patient who chose to breastfeed. We also get calls on the Perinatal HIV Hotline about infant feeding. I believe in patient autonomy and informed choice and want providers to have tools to help guide those conversations."
- "It is a reproductive justice issue.... how women/lactating people living with HIV choose to feed their babies. And, having done some research in the field, there are still unanswered questions like optimal ARV regimens to prevent transmission during lactation. This is the next frontier in HIV medicine and prevention."

** "Women" is used throughout this section, reflecting the language used in the survey

Recommendations for Actions Moving Forward

In order to carry out the goals listed in the Consensus Statement, participating experts have developed an initial list of short- and long-term actions and recommendations based on discussions and feedback from the initial convening. The authors look forward to engaging with a wider group of stakeholders to assess existing and potential work in this area and to advance the following efforts.

Actions to Improve Infant-Feeding Support for Parents Living with HIV

- Further develop and expand a diverse, multi-disciplinary, multi-sectoral coalition of stakeholders working at the intersection of HIV and infant feeding to monitor and advance these efforts
    - To include: people living with HIV; clinicians across disciplines (infectious disease, OB/GYN, pediatricians, etc.); midwives; doulas; social workers; legal experts; social scientists; child protective workers; community health workers; lactation consultants; case managers; networks of people living with HIV; policymakers; government officials; ethicists; advocates; and others
- Outline strategies to ensure infant-feeding programming for parents living with HIV explicitly includes trans men and other birthing parents who do not identify as women
- Create database of U.S. and Canadian partners (including providers, peer educators, community-based organizations, and internet-based resources) that reach parents living with HIV wherever they are and however they access their information; to be leveraged in information gathering and dissemination
- Gain insights into the infant-feeding information people living with HIV want and how they wish to access it; produce and disseminate identified resources through partners in database
- Develop an online support community for parents living with HIV to share infant-feeding experiences (anonymously, where necessary)
- Develop community-facing campaigns to improve public understanding and support for birthing and breastfeeding among parents living with HIV
- Conduct literature/research review to identify all relevant research on breastfeeding among women living with HIV
- Develop and promote research agenda that leverages existing findings, seeks novel applications of relevant data, and addresses knowledge gaps
- Consolidate current clinical practice standards and guidelines around best practices to minimize the risk of HIV transmission via prophylactic regimens for babies who are breastfeeding across geographies and provider associations
- Create a practice transformation model for supportive clinical settings and culturally responsive educational programming that center women's lived experiences, consider factors beyond potential HIV transmission, employ a harm reduction lens, and address racial bias among providers
- Create process to hold accountable providers and systems who misinform and/or punish women
- Work with organizations that publish HIV-related guidelines to ensure they are up to date, reflect best practices and complexities of infant feeding, and are consistent across disciplines; develop comprehensive postpartum guidelines for women living with HIV
- Identify key stakeholders and experts in intersecting advocacy fields; work to explicitly address and ultimately change the legal environment that allows women living with HIV to be criminalized if they choose to breastfeed

Actions to Address Underlying Structures that Impede Progress on Infant Feeding Among Parents Living with HIV

- Address the many ways that instruction to not breastfeed is not neutral and can cause medical as well as emotional and other kinds of harm
- Develop implicit bias training for providers to help them critique their biases when they assume that some clients (often those who are white or have a higher formal education level) can be "trusted" with information that impacts their health, while others cannot
- Identify where differences in research context (North/South divide) are relevant to the dissemination of findings and where the reticence to do so is rooted in racism and white supremacy
- Address the structural conditions that affect the level of support that parents receive during the postpartum period, recognizing that breastfeeding is challenging, and support lacking, even for those with a high degree of privilege and access
- Develop support structures and policy advocacy for parents living with HIV who choose not to

breastfeed, including making formula or banked milk readily and easily available (and covered by private and public insurance)

For additional resources on this topic, please click here***.***

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