

BREASTFEEDING AND HIV: Improving Care and Support for Women Living with HIV

AUTHORS: Bridgette Picou, Jenna Conley, Ciarra Covin, Olivia G. Ford, Krista Martel

BACKGROUND

Breast/chestfeeding is considered the healthiest infant-feeding option for the general population and the standard of care for women and other birthing parents living with HIV in resource-limited regions worldwide. Limited research on breastfeeding and HIV in high-resource settings has resulted in a lack of education and clinical standards for providers in these areas to support informed infant-feeding decision-making among women living with HIV. This deficit compounds existing deterrents to informed decision-making for many women living with HIV, such as racism, HIV criminalization, and misogyny. Moreover, HIV transmission risk is often the only factor considered by providers when they counsel

feeding decisions. Focus on the potential risk of HIV transmission as the sole determinant fails to acknowledge both the right to bodily autonomy and the numerous potential benefits of breast/ chestfeeding for both parent and child.

a birthing parent living with HIV in their infant-

All I wanted to do was feed my baby. I was not seeking approval, I just needed support." Ciarra Covin, Program Manager

DESCRIPTION

The Well Project, a nonprofit organization whose mission is to change the course of the HIV pandemic through a unique and comprehensive focus on women and girls, strives to increase knowledge and expand access to information around breast/chestfeeding and HIV. In order to do so, The Well Project engages with both women living with HIV across the gender spectrum and providers to identify key areas of need and concern. Ultimately, by identifying these priorities through engagement with a broad group of stakeholders, our goal is to provide clinicians

Language matters:

At The Well Project, we use "breastfeeding" and "breast/chestfeeding." The Well Project focuses on cis and trans women living with and vulnerable to HIV and strives to be inclusive of trans men, nonbinary individuals, and all others living with HIV who wish to explore these options.



and other providers with the tools necessary to diminish HIV stigma, increase awareness of current research, and encourage a holistic approach to wellness and infant-feeding choices. As an initial step in this process and in partnership with the International Community of Women Living with HIV - North America, The Well Project convened a multi-disciplinary, multi-sectoral group of experts and executed a survey to identify these priorities and challenges among women living with HIV.

how vital it is to empower women living with HIV to feel free to have children and feed them as they see best." Porchia Dees, CAB Co-Chair

As a woman born with HIV, I can tell you

LESSONS LEARNED

In an effort to identify and highlight existing gaps in this area, The Well Project conducted a survey among expert stakeholders (n=21) in Canada and the United States in 2020, identifying the following priorities and challenges:

CHALLENGES

Disregard for the bodily autonomy and decision-making ability of people living with HIV and birthing parents

Lack of understanding among providers of existing breastfeeding research, its implications, and limitations

Inadequate resources for providers to support the infant-feeding decisions of women living with HIV and lack of knowledge around harm reduction strategies



PRIORITIES

Additional research to understand HIV transmission through breast milk among women living with HIV who have sustained viral suppression

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

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



To address these opportunities, The Well Project launched BEEEBAH (Building Equity, Ethics, and Education on Breastfeeding and HIV) in 2021. This multi-faceted initiative expands on The Well Project's existing efforts to increase knowledge and expand access to information around breast/chestfeeding. Through resource creation, leadership development, and collaborative efforts, **BEEEBAH** strives to ensure women living with HIV can make informed infant-feeding choices.





CONCLUSION

While the 2021 Perinatal HIV Guidelines recommend the use of formula over breastfeeding, they also advise that people living with HIV who have questions about breastfeeding should receive patient-centered, evidencebased counseling on their options and those who choose to breastfeed be supported in order to minimize the risk of HIV transmission. Ensuring that women and other birthing parents are able to make the best infant-feeding decisions for their families will require the development and broad dissemination of comprehensive, educational resources to both providers and parents living with HIV. Additionally, more research is needed, particularly among

women living with HIV in high-resource settings; and policy must be updated to reflect the current and emerging evidence.

Endeavors in this work are 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. It is essential that all stakeholders, including birthing parents, providers, policymakers, and researchers, recognize the ways in which structural racism and persistent HIV-related stigma contribute to inequities in the breastfeeding landscape.

[Breastfeeding] represents one of the current frontiers of HIV stigma/moral panic...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."

Marielle S. Gross, MD, MBE