

LISTENING TO WOMEN:

Supporting Informed Decision-Making on Infant Feeding and HIV

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BACKGROUND

Breast/chestfeeding is considered the healthiest infant-feeding option for women worldwide, and is the standard of care for women living with HIV in resource-limited settings.

A paucity of data on breastfeeding and HIV in high-resource settings means that most guidelines in these settings take a risk-averse approach, recommending exclusive formula-feeding for women and birthing parents living with HIV. UK guidelines state that breastfeeding can be supported if the birthing parent has an undetectable viral load. Elimination of HIV transmission risk often overrides other concerns in these settings, overlooking important factors including health and wellbeing benefits of breastfeeding; family and cultural expectations; and lack of financial resources to formula feed. This limits healthcare providers' ability to support informed infant-feeding decision-making in this population.

In both the US and the UK, women and other birthing parents living with HIV are disproportionately from racialized communities and/or face poverty; infant-feeding experiences are therefore embedded in the intersecting forces of structural racism, gender bias, and economic injustice. Further, in the US, 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.

In early 2023, the US Perinatal HIV Clinical Guidelines were updated to recommend that women and other parents living with HIV receive evidence-based, patient-centered counseling to support shared decision-making about infant feeding. Consistent with the UK guidelines, the updated guidance advises providers to support parents living with HIV who are taking antiretroviral therapy with a sustained undetectable viral load and make the choice to breastfeed. It is hoped that these changes will facilitate broader research in this area. Stakeholder education will continue to be key to ensure policy and practice shift to reflect these changes.

Scan the QR code for more information.



MATERIALS/METHODS

Two groups are responding to the demonstrable need for greater person-centered research, policy, and education on infant feeding for women and birthing parents living with HIV.

The Well Project (www.thewellproject.org) is a US-based non-profit organization that leverages web-based technology to improve health outcomes and quality of life for women living with and vulnerable to HIV across the globe. The Well Project conducts periodic surveys to assess the impact of its programming, and gain insights into the experiences of women living with HIV across the gender spectrum to identify areas of need for education, support, advocacy, research and/or policy changes. The Well Project's 2021 survey (n=212 women living with HIV) included an optional section on breastfeeding experiences among women living with HIV (n=33), which is a key topic of advocacy and education for the organization.

Nourish-UK is a UK-based qualitative study exploring how women and birthing parents living with HIV decide how to feed their newborn babies. In April 2021- January 2022, the team (comprising providers, social scientists, and women living with HIV) conducted semi-structured interviews with 36 cisgender women living with HIV who were either pregnant or had given birth within 12 months. Participants were recruited via HIV clinics and charities. Data were analysed thematically using NVIVO12 software.

In this document, the term "breastfeeding" is used to describe feeding a child one's own milk. It is important that providers assess and use parents' preferred terminology when counseling them about infant feeding - and consult community-based resources for more information about inclusive language around gender in healthcare settings. Some transgender men, nonbinary, and/or gender-diverse individuals may prefer using a term such as "chestfeeding" rather than breastfeeding.

RESULTS

The Well Project and Nourish-UK both document similar experiences among women living with HIV in two high-income regions. (Both studies were planned to be gender inclusive, but only heard back from participants who self-identified as cisgender women.) Greater access to information and support from providers were key needs expressed by women in both studies.

THE WELL PROJECT

In The Well Project's survey, many respondents faced challenges if they were interested in breastfeeding their child, or if they decided to do so. These include:

"[We need] more research and education in breastfeeding safety, [and] policy should be implemented by listening to the voices and needs of women living with HIV who want to get pregnant and breastfeed" – Survey participant

Providers who were not well informed about the minimal risk of HIV transmission through human milk when on suppressive antiretroviral therapy (43%)

Lack of support (32%)

Fear of criminalization (32%)

The issue of providers not being well-informed regarding the risk of transmission was 45% higher among Black women compared to white women

"I was immediately told I would not be able to breastfeed my baby" – Survey participant

NOURISH-UK

Nourish-UK participants reported inconsistent access to infant-feeding information from their multidisciplinary teams; information was sometimes incomplete or inaccurate.

"I was just made to believe that [breastfeeding] was a high risk of transmission and that it was, you know, just a no go [...] I didn't know that there was an option to do it in a safer way, especially as I was undetectable way before I gave birth." - Amy

Providers' apparent limited awareness of national guidelines and data were a barrier to open conversations about infant-feeding options

Half of all respondents described not feeling supported in shared decision-making, including some who were actively discouraged from breastfeeding despite meeting the criteria to be supported to breastfeed

A minority of women relied on self-advocacy and personal research to obtain infant feeding

The majority of women stated that supportive non-judgemental clinical conversations about their feeding options were important.

"...when I ask [the clinicians] questions [about the UK guidelines], they treat it like, 'Oh she doesn't have enough knowledge, or she may not understand'" - Lana

RESULTS

- When providers are aware of a fuller range of infant-feeding considerations and describe them in an informed way, women living with HIV feel more confident about whatever decision they make
- Ensuring parents living with HIV are able to make the best infant-feeding decisions for their families will require access to comprehensive, educational resources for providers and parents
- More research is needed to deepen knowledge and inform practice in a range of areas including basic science, clinical learnings, and more. Related policies must reflect current and emerging evidence.
- Efforts in this arena are strengthened when providers are responsive to infant-feeding inquiries from parents living with HIV, recognize their autonomy, and trust their ability to make informed decisions

The Well Project and Nourish-UK teams would like to thank all who participated in our studies and who shared their personal experiences.

