Women living with HTLV-1 should have the opportunity to make informed decisions on prevention of mother-to-child transmission

No one could disagree with the title of the Comment by Jane Fisher[1] in response to our health economic research[2]—ie, "Recommendations against breastfeeding require consultation with women for effective implementation". Such consultations with women living with human T-cell lymphotropic virus type 1 (HTLV-1) shaped our research,[2] while the absence of antenatal screening excludes women from any shared decision making. We endorse the need for antenatal screening but ensuring optimal resource allocation is key and drove our economic analysis of HTLV-1 antenatal screening. Because we used the perspective of the Ministry of Health, the costs to parents, as suggested in the Comment,[1] cannot be considered.

As stated in our study,[2] exclusive formula feeding prevents 85% of vertical transmissions and is the most common recommendation for women living with HTLV-1.[3] Literature and patients' perspectives indicate that acceptance is high[3,4] and we highlighted the importance of ensuring that such an intervention is acceptable, feasible, affordable, sustainable, and safe.[2]

We strongly advocate for breastfeeding and initiatives such as Baby-Friendly Health are more than welcomed. However, such advocacy should not be detrimental to women who, for whatever reason, opt not to or cannot breastfeed. Women must have autonomy to make informed decisions and receive the correct support. Regarding HTLV-1, to make an informed decision, women must know their serostatus and have access to proper care and accurate information to weigh the risk and benefits of interventions. Accurate information is key, and, in many areas, health-care professionals have scarce knowledge about HTLV-1,[4,5] resulting in an underestimation of the effect of HTLV-1, and a paternalistic approach that does not mirror the community perspective.[5] Statements that breastfeeding is the major source of maternal love and imperative for a healthy life are detrimental to people living with HTLV-1 or other conditions where breastfeeding might lead to harm. In addition, the stigma that women living with HTLV-1 might endure, because of their feeding choice, should not influence the decision not to screen, it should be catalytical for change in society.

We strongly agree that women must be consulted. Unfortunately, those living with HTLV-1 have been ignored for more than 40 years. Few policymakers have been listening to their demands to implement policies to avoid new infections and protect future generations. Women must have the opportunity to know if they are infected by HTLV-1. Women living with the virus must receive accurate information, have autonomy to make their decision regarding prevention of HTLV-1 mother-to-child transmission, and receive support regardless of their choice of feeding strategy.

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4 Pan American Health Organization. The response to HTLV in the framework of maternal and child health. 2022. https://iris.paho.org/handle/10665.2/56888 (accessed May 7, 2023).

5 Fowler F, Einsiedel L. A qualitative study exploring perceptions to the human T cell leukaemia virus type 1 in central Australia: barriers to preventing transmission in a remote aboriginal population. *Front Med* 2022; **9**: 845594.