

Women Know Best, Work with Us

Decision-making about Infant Feeding while living with HIV

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Objectives

UK HIV pregnancy guidelines recommend formula feeding as preferable, but women wishing to breastfeed should be supported. We explore infant feeding decision-making with (i) women living with HIV (4M Mentor Mothers UK-based Network, 4MNet); and (ii) HIV clinicians.

Methods

Qualitative study using peer-led participatory action approach. Six case studies conducted July-August 2020 by phone and email (four Mentor Mothers, two clinicians). Data analysed thematically by women living with HIV, with respondent validation from Mentor Mothers; emergent findings discussed with 4MNet Advisory Group.

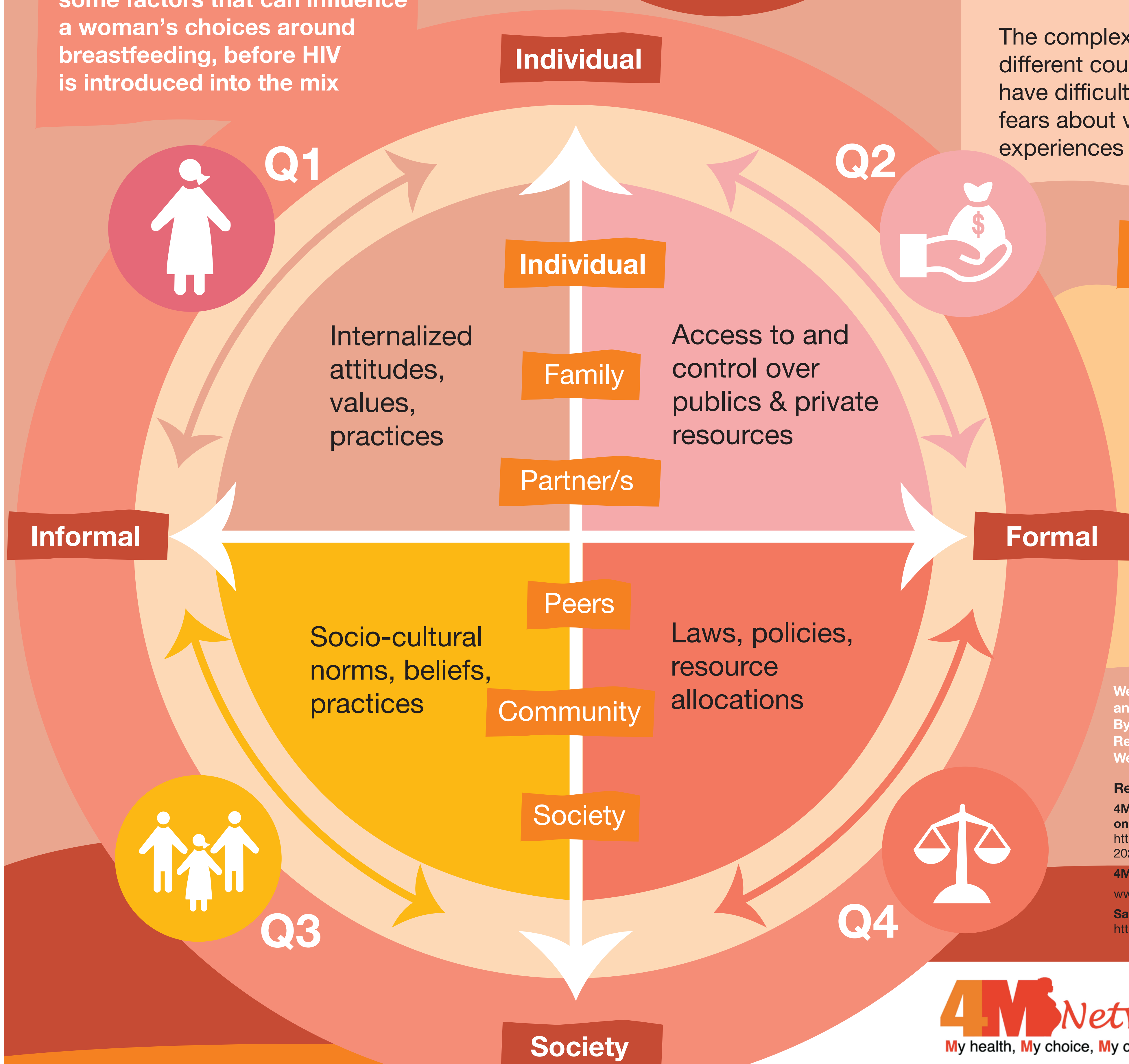
You can only make good choices and well-informed choices if you are given the right non-judgmental information in the first place. In most cases women aren't getting this.
Mentor Mother

Some healthcare professionals have difficulty supporting HIV positive women who breast feed because they are fearful of the risk of transmission.
HIV consultant

Having now supported more than 20 mothers living with HIV to breast feed and spending much more time discussing this option with others, I would say that I have found that by being more supportive to women when they are making a decision about infant feeding I have found a stronger bond with my patients who are then more likely to be comfortable being open with me and to continue to look after themselves"
HIV consultant

I am supporting a woman who has just had her first child she has now felt ready to breast feed for the first time and it is so special for her to feel fulfilled as a woman to have this experience also it has been a real journey for her and because she's getting the right support from her multidisciplinary team she is now able to do this
4M Mentor Mother

ALIV[H]E Framework: some factors that can influence a woman's choices around breastfeeding, before HIV is introduced into the mix



Results

Participants described infant-feeding decisions as fraught with difficulties and others' judgements, made within a complex physiological, psycho-social and emotional matrix. High levels of routine blood tests of mothers and babies can be disincentives to choose breastfeeding, with women feeling judged and blamed.

Decisions were influenced by multilevel factors in the following domains:

- individual (resources)
- interpersonal (family relationships)
- community (sociocultural attitudes towards infant feeding) and
- societal (policies, laws, financial resources)

The complexity was amplified by apparently conflicting guidance in different countries. Healthcare professionals in high-income countries can have difficulty supporting breastfeeding; some appear reluctant through fears about vertical transmission. Support from peers facilitated positive experiences of infant feeding.

Conclusions

- Women living with HIV have agency and can make informed choices about infant feeding.
- Value-free, up-to-date, comprehensive information aids decision-making.
- Respect and non-judgmental support for however a woman chooses to feed her baby is central in building trusted collaborative relationships with professionals, enables infant-feeding experiences to be positive and life-enriching, and upholds women's sexual and reproductive health and rights.

We wish to acknowledge the ongoing support of 4MNet's incredible Mentor Mothers and the amazing Steering Group members: Jane Anderson; Susan Bewley; Laura Byrne; Rageshri Dhairyawan (Chair); Fiona Hale; Vicky Johnson; Longret Kwardem, Rebecca Mbewe, Angelina Namiba, Shema Tariq (Interim Chair); Pat Tookey; Alice Welbourn; and Alison Wright. Massive thanks to our funders and partners.

References

4M Mentor Mothers Network CIC & Salamander Trust, 2020, Position Paper on Infant Feeding for women living with HIV
https://4mmn.org/wp-content/uploads/2020/12/4M_Breastfeeding_PaperAugust2020.pdf

4M Mentor Mothers Network CIC website

www.4mmn.org; Twitter @4MProject

Salamander Trust et al ALIV[H]E Framework (UNAIDS, 2017)

https://www.unaids.org/en/resources/documents/2017/ALIVHE_Framework