Author’s response to reviews

Title: "I beg you...breastfeed the baby, things changed": Infant feeding experiences among Ugandan mothers living with HIV in the context of evolving guidelines to prevent perinatal transmission

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Author’s response to reviews:

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Dear Editor:

Thank you for reviewing our manuscript “I beg you…breastfeed the baby, things changed”: Infant feeding experiences among Ugandan mothers living with HIV in the context of evolving guidelines to prevent perinatal transmission.” The manuscript has been revised to reflect the important points raised by the reviewers. We thank the reviewers for their constructive comments and suggestions, and believe that these have strengthened the manuscript. We have summarized and detailed the revisions below. We have also included two versions of the revised manuscript, one with tracked changes and one clean.

Editor Comments:

1. In addition to responding to reviewer comments, ensure that your manuscript adheres to consolidated criteria for reporting qualitative research, and attach a checklist as supplemental file. COREQ guidelines are summarised in: Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International journal for quality in health care, 19(6), 349-357.

- Response: Thank you for this comment. We have reviewed and updated the Methods section to provide additional information demonstrating adherence with the COREQ guidelines. We have also attached the checklist as a supplemental file.
Reviewer 1

1. Breastfeeding and HIV has been a moving target ever since Philippe van den Perre described in in 1992. The authors are right in problematizing breastfeeding again after the 4th shift in guidelines after the millennium-shift.

- Response: Thank you for this comment

2. Typography, lots of 'full stops' before brackets. Funny looking at two set of line numbering, I use the numbers closest to the text.

- Response: We have reformatted the text to address these comments.

Introduction

3. Be more precise and tell exactly which relevant late PMTCT studies that have pushed transmission down and to which degree, using B+ - to which level - and how this is in operational studies in sub-Saharan Africa being LICs. E.g Kesho - Bora and later studies.

- Response: Thank you. We were mindful that this work has been published in detail elsewhere, but have included key evidence in Table 1 and updated the citations in the Introduction.

4. For the second paragraph it's important to stress not only the benefit of bf, but also present the risk of non-bf among WLWH. The operational study being most relevant here is Kagaayi from Rakai (http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0003877 ). Not bf can be short-term, directly deadly. More children dying from other causes than HIV - and for infected children bf extremely important.

- Response: Thank you for this comment. We have modified the language to more strongly reflect the risk of non-breastfeeding among WLWH and cited the study noted above.
5. I think it is "old" now to stress the perspectives from HICs, and I don't think there is any need in the PMTCT community to bring back the 2001 perspectives. Rather go in depth on the 2010-2016 guidelines - rather problematize that the 'end-point' guideline (how long should they bf) is still a bit unclear. What's the change from 2010-16 and within which paradigm is this study done.

- Response: We have removed the comparison to HICs as well as the reference to the 2001 guidelines in response to these comments.

6. The references to the statements in line 82 should be relevant for the later period (2010 - >) and some examples could have been informative.

- Response: Thank you. We have revised and limited references to those from 2010 onward.

Methods

7. It is a bit unclear if the study included women who were temporarily giving birth at both sides of the B+-implementation.

Response: We have clarified language to describe that all participants gave birth after Option B+ was implemented at the regional HIV treatment clinic. Study interviews were conducted between February-August 2014 with babies born between March 2012-October 2013. Although Option B+ was implemented in Uganda in 2013 (in accordance with WHO guidelines), the Immune Suppression Syndrome (ISS) clinic, the Mbarara regional HIV treatment clinic, rolled out Option B+ in January 2010, earlier than the rest of the country [1].

8. It also looks funny saying 'at that time WHO's infant feeding guidelines formed the basis for Uganda's national guidelines for PMTCT and infant feeding - Uganda has all the time been considering and followed a lot of the WHO guidelines. It would have been clearer to say what they then had implemented and how that overlapped with the data collection.

- Response: Thank you for this comment; we have clarified the language in this section.
9. How was the women stratified into HSCL-categories? The whole paragraph on selection of participants should go deeper and explain the sampling.

- Response: We explain in more detail that the sampling by HSCL categories occurred as part of the larger study focus on postpartum depression. In the current paper, infant feeding was an emergent theme and the HSCL scores did not inform the data analysis. We note this in the Methods and the Discussion.

10. Did the 2 coders do separate coding for 20 interviews? Why that? It would have been more sound with double-assessment rather than a split of data. Funny use of kappa statistics.

- Response: We have updated the description of the coding to clarify that to ensure consistent understanding and interpretation of the codebook, two coders coded the same four transcripts, coding was compared, and discrepancies resolved through discussions with the analysis team. The codebook was then updated and the remainder of the interviews were coded independently.

11. If the study women are from Mbarara, are they then 'rural'?

- Response: While the study took place in Mbarara town, many participants resided in rural areas surrounding the town. For clarity, however, we removed the ‘rural’ description of the town.

Results

12. Generally the section is too long and the authors should make an effort shaping it better.

The data should be rich enough not to bring in other references in the result text. Please stick to the own data.

- Response: We have edited the results section to focus on the data from the women interviewed and moved references to others’ findings to the Discussion section.
13. The data themes seems valid, but the data and narratives used to illustrate that doesn't seem to fit entirely under each sub-heading, 1 188, 194 on 'risk my son.' The authors should go together and make sure the points come out more clearly - that could be done by 'shorter' texts. Instead from 1 177-183 giving lots of information - I would be much more interested in what the data says. If really such a large analysis team has worked on this - what is the inductive results?

- Response: As suggested, we updated the description of the data themes using shorter texts and a sharper focus on the most pertinent data.

14. The discussion should be much more closely to the result-findings.

- Response: We have amended the discussion to more closely mirror the results.

15. A paragraph on strengths and limitations of the study is needed. Particularly, the challenge of changing recommendations is maybe not a 'fair' period on the health workers?

- Response: We added a paragraph on study strengths and limitations.

16. Is given the limitations of the study this study strong enough for giving recommendations? Maybe, instead of saying what others should do (here an imprecise size 'infant counselling') - talk more about this from the 'how' perspective? Research needed? How could such studies inform future implementation and training of health workers?

- Response: We have amended the implications and recommendations to include future research priorities.

17. Did 7 people analyse the data?

- Response: While two people coded the interview transcripts, seven members of the team were involved in the data analysis through iterative discussions of the codebook and emerging themes. We have clarified the data analysis process in the methods.
18. I think the paper has been submitted a bit prematurely. It seems either not finished or not newly updated.

- Response: Thank you for your helpful and insightful comments. We believe that in attending to the reviewers’ constructive feedback, the revised manuscript is greatly strengthened.

Reviewer 2:

19. Nicely written paper with useful information. It would be helpful if you included a sentence about the educational level of the mothers.

- Response: Thank you. We have added education level of the mothers to the Results and to Table 2.

Reviewer 3:

20. This paper provides relevant information. Some clarifications are needed.

- Response: Thank you.

Abstract

21. Line 32. Actually, the more recent guidelines recommend breastfeeding up to 24 months, as the authors reported in Table 1, in the Background section (pag. 3, line 16) and in the Discussion section (pag. 13, line 315).

- Response: Thank you for this comment. We originally had included reference to the 2010/2013 guidance in place during the time of the study, however, the current 2016 guidelines are the most appropriate to reference in the abstract. We have changed the abstract to indicate 24 months.
Methods

22. Pag. 4. Line 98. The authors say that the time of the study is 2014, actually the time of the study is between March 2012 and October 2013, period of breastfeeding of included children.

- Response: Thank you. We have clarified the study timeline by outlining that the interviews were conducted between February-August 2014, for babies born between March 2012-October 2013, with participants reporting on postpartum experiences (including infant feeding) between March 2012-August 2014.

Results

23. Pag. 6. The authors say that 20 women were interviewed and report in Table 2 their characteristics. However, in line 43, they say that 14 women described an infant feeding experience in response to open questions about challenges and opportunities experienced during the first six months postpartum. So, which is the number of women really included in the study?

- Response: The number of women enrolled and included in this qualitative study was 20. Infant feeding was an emergent theme from the interviews and not the primary purpose of the study, such that women who did not talk about infant feeding were still part of the analysis. Of the 20 women who were interviewed, 14 described infant feeding experiences.

24. Page 6. Lines 143-148. The authors report that 10 women described an infant feeding practice inconsistent with reigning WHO recommendations. However, later when they describe these women in lines 147-148, they refer to 14 women.

- Response: Thank you for noting this error. We have clarified this in the revised results section.

25. Page 6. Lines 149-152. N. 2 and N. 3 seem to overlap. I wonder if these two could be combined.

- Response: While conducting the analysis, the co-authorship team also debated whether to join these two sections. Based on the reviewer’s comments, we have combined these two sections.
26. Table 2. Median age is 38 (with a wrong IQR) while in the text is 33.
- Response: Thank you for noting this typo in Table 2, it has been corrected.

27. Pag. 8. Lines 177-197. The two cases reported are very similar: both describe early weaning, lack of mixed feeding and being admonished by the doctor.
- Response: We agree that the cases are similar, but chose to retain both to highlight the role of the partner in one case.

Reviewer 4:

28. Nicolas Nagot (Reviewer 4): My general comments first relates to the use of the 'perinatal HIV transmission' term throughout the paper. If this term is correct, then the paper misses the point that HIV exposure continues throughout the breastfeeding period, i.e. it does not stop one week after birth. I think this term is inappropriate as the perinatal period commences at 22 weeks of gestation and ends 7 days after birth. When referring to the contribution of breastfeeding in HIV transmission, the term postnatal transmission is generally used as it encompasses the whole duration of HIV exposure, i.e. the whole duration of breastfeeding, whatever it is.
- Response: We have replaced perinatal with postnatal throughout the text.

29. The main concern is that the interpretation of the findings is difficult without knowing the content and intensity of infant-feeding counselling the participants were exposed to and the level of training of the health care workers regarding the WHO guidelines. The challenges, questions, and navigation of women regarding the risk of postnatal transmission reflect a lack of clear messages from health care workers. The study findings can be seen as the outcome of the counselling activities regarding infant feeding.
- Response: Thank you. We have added additional text to acknowledge the lack of data on the counselling women received.
30. The study rationale is a bit confusing. The current infant feeding guidelines have been elaborated in that sense. Yes, 'WHO guidelines have been criticized for inadequately acknowledging the individual, social, cultural, and health system expectations' (line 79), but it was because shorter durations of breastfeeding were highly recommended, with the associated risk of stigma for WLWH.

- Response: Thank you for this comment. We further clarified the study rationale in the Introduction and Discussion. This paper is the result of emergent data from a study that did not set out to explicitly explore this topic (i.e., confusion about infant feeding guidelines).

31. In addition, there seems to be some confusion between early discontinuation of breastfeeding and not complying with exclusive breastfeeding practises. Not complying with the definition of exclusive breastfeeding, which is very strict (giving only once non-breastmilk food breaks the rule), does not mean that breastfeeding is then stopped. The references cited (29, 31-35) do not support that WLWH discontinue breastfeeding by themselves; as mentioned in the Ugandan paper by Homsy et al., guidelines at the time recommended exclusive breastfeeding for 3-6 months followed by rapid weaning and replacement feeding. As a result, women were counselled to have stopped breastfeeding at 6 months maximum, which explains the short duration of breastfeeding reported.

- Response: Thank you for the comment. The studies cited experiences of women who stopped breastfeeding 'early' relative to the guidelines that were in place at the time; we have modified the text to reflect this.

32. The selection of participants from a cohort, based on HSCL scores raises concern of selection bias. As highlighted by the very high rate of viral suppression (95%), these women are compliant and regularly followed at health centres, exposed to repeated counselling which is likely not the case of the 'average' women followed in HIV outpatient clinics.

- Response: We agree and have included a limitations section which comments on the exceptional features of our study participants. Indeed, the fact that our participants (accessing and retained in relatively high quality care, adherent to therapy) experienced such challenges with evolving guidelines suggests that our participants describe a best-case scenario.
Methods

33. Line 108: It is difficult to figure out how women were selected for the study, how many were selected from score ranges.

- Response: We have enhanced the description in the revised Methods and Results sections. Please see our response to Reviewer #2 above.

34. The interview guide was not available, as no supplementary material was annexed.

- Response: The interview guide has now been appended. It is important to note that infant feeding experiences were emergent from the data and not the focus of the interview guide.

Discussion

35. Line 331: 'As the 2016 guidelines recommend breastfeeding for WLWH up to 24 months and beyond, there may be additional confusion and concerns among healthcare providers and patients'. These recent guidelines stress that infant feeding choices are no longer a determinant for HIV transmission. What matters is that women are taking their HIV drugs correctly and that they are virally suppressed. The women should be reassured that i) the risk of transmission is quasi-null in this case (as it is for transmitting HIV to their partner if HIV-negative) and ii) the risk of stopping breastfeeding too early or to use formula feeding much outweighs the risk of HIV transmission. Basically, infant feeding counselling should now be the same whatever the HIV status, as long as the mother is compliant with her HIV treatment. The authors may discuss that, unfortunately, the situation is different from that in the UARTO cohort; in many African settings, up to 50% of breastfeeding women are not virally suppressed 6 months after child birth.

- Response: Thank you for this comment. We agree that women should be supported to adhere to ARTs and that if they have sustained viral suppression, then they should be reassured of a near zero risk of postnatal transmission through breastfeeding. Women (and partners and healthcare providers) should also be reassured that the risks of not breastfeeding outweigh the risks of HIV transmission. Although perhaps more relevant to debates underway in high-resource settings where breastfeeding is discouraged and in some settings, illegal, the data on U=U for breastfeeding are not as conclusive as they have been for sexual HIV transmission [2].
- For the purposes of our infant feeding analysis among women in Uganda, however, a more relevant concern is, as the reviewer mentions, the high rates of disengagement from care and sub-optimal adherence in the postpartum period [3], with a high proportion of breastfeeding women not virally suppressed six months after childbirth [4]. A recent systematic review of HIV transmission risks to infants of WLWH receiving lifelong ART found a pooled postnatal transmission rate by six months of age of 1.1% in women who were advised to breastfeed for six months. The pooled estimate for postnatal transmission at 12 months of age was 3.0% [5]. This is all to say that we agree with the reviewers emphasis that infant feeding counselling must also include encouraging early and regular HIV testing, early initiation on ART, and support throughout the cascade of HIV care to achieve a sustained undetectable viral load. We have now reflected this feedback in the Discussion.

We trust that we have addressed all of the concerns and suggestions offered by the reviewers. On behalf of my co-authors, I would like to thank you for your interest in our manuscript. Please do not hesitate to contact me if you have any questions or comments.

Sincerely,

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References


