Reviewer's report

Title: 'They have exposed us so much'. Experiences of stigma among women living with HIV attending SRH services in Kenya: a qualitative study

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Reviewer: Janet Turan

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Review of “‘They have exposed us so much’. Experiences of stigma among women living with HIV attending SRH services in Kenya: a qualitative study”

This manuscript addresses the important topic of how fears and experiences of stigma may impede use of essential sexual and reproductive health (SRH) services by women living with HIV in a sub-Saharan African setting. The findings of this qualitative study certainly resonate with findings of multiple other studies conducted in sub-Saharan Africa in recent years. In fact, it is a little hard to see what this manuscript adds to what we already know about HIV-related stigma and discrimination faced by reproductive aged women in sub-Saharan Africa. However, the potential contribution of this paper lies in the specific focus on use of family planning and postnatal care services by these women. Yet it seems like the authors could have done more to focus on these aspects and present unique findings that are particularly of relevance for these SRH services. Strengths of the paper include the use of qualitative methods to elucidate women’s concerns and some very interesting findings on a) some women’s preferences for non-integrated HIV-specific services and b) the reports of women that they are able to overcome fears and experiences of stigma and adhere to antiretroviral therapy (ART). One problem is that although the research was conducted within a larger study examining HIV and SRH service integration, it was unclear what types of services were being utilized by the women interviewed for this study (SRH services integrated with HIV care and treatment? HIV clinics that were also offering FP and other SRH services?). In addition, more methodological details are needed to understand if the study met criteria for rigor in qualitative research. Finally, the authors have not pointed out the limitations of their research in the Discussion section. Some editing of the English language is needed. Specific comments by section are given below.

Major Compulsory Revisions:

Abstract:

1. Results: I think the term more frequently used in the stigma literature to describe fears of stigma, “anticipated stigma” is more descriptive and clear than the term “perceived stigma”. I would suggest using that term throughout and citing some of the literature on clarifying the meaning and the effects of anticipated stigma.
Introduction:

2. Although the authors indicate that the unique contribution of this study is its focus on FP and PNC clients, I fail to find many findings that are specific to this group of clients or these services. The findings are very much the same as those reported in other client populations, e.g., antenatal clients.

3. I was unclear why the authors did not aim to explore internalized stigma as well. This is in fact the dimension of stigma that has been most frequently associated with poor ART adherence in the literature, and perhaps that is why this study did not find a link between stigma and poor adherence. On the other hand, some findings related to internalized stigma are reported in the study findings (even though this is not stated as one of the aims in the introduction).

Methods:

4. Participants and procedures: The authors should give some more background on the services/clinics from where the study participants were recruited and how the women were recruited. Were these services where HIV-SRH were integrated? HIV clinics that also offered FP services? Some other configuration? More information on the community and health service contexts is needed.

5. Participants and procedures: More information is also needed on the women recruited for the study. Were they all HIV-positive women? I assume so, but this was not clearly stated. We need more information on how these women were selected and if there was any attempt to sample women with different characteristics to make sure variation was captured. It is important to understand if this was somehow a select group of women with different views than those of the general population of women using these services.

6. Participants and procedures: Were the interviews conducted at the health facilities? Who were the interviewers? Were the interviewers perhaps perceived to be HF staff?

7. Interview guides: Were the topics included in the final interview guides pre-determined (and how were they originally developed) and/or did they include emergent themes from the initial interviews?

8. Data analysis: More detail on the coding and analytical processes would be helpful. How was the coding scheme developed? Were the data coded by one person or a team?

9. Were any methods used to verify or check the findings?

Results:

10. How were the three "parts" for presentation of the results decided on? Were these the main themes emphasized by the women? Main things affecting adherence?

11. Section 3.1, Page 6: One wonders what factors may have influenced the fact that no women reported any experiences of enacted stigma at a health facility. Where the interview was conducted (perhaps at the HF)? Perceptions of the interviewers as part of the HF team? Also, one could argue that lack of protection
of confidentiality resulting in unwanted disclosure is a form of stigma/discrimination.

12. Section 3.1, Page 6: The first quotation about being forced to disclose when giving birth at the health facility is a good one, but isn’t this article supposed to be about FP and PNC services? Or is it just that the participants were recruited from those clients? Again, I think the unique contribution of this article would be sharper, if the data presented were focused on women’s experiences with FP and PNC services.

13. Section 3.1, Page 7: It would be helpful to have some specific information about how women’s HIV status would be disclosed in a FP clinic setting. Would FP providers ask women questions about their HIV status or revealing their HIV status in an open area where others could hear?

14. Section 3.1, Page 9: The findings on the women’s preference for separation of services are interesting. It is usually argued that integrated services are more anonymous and confidential than having to be seen going to a separate HIV clinic and thus less stigmatizing. This argument is usually made to support integrated services. However, it seems that these women appreciate the freedom to talk and social support in an HIV clinic more.

15. Section 3.2, Page 9: When the authors state that they found no link between stigma and fertility intentions, it would be good to cite literature that would suggest that there is a link. It sounds like authors are indicating that this is surprising finding.

16. Section 3.2.2, Pages 12-14: The findings on breastfeeding are not very clear. It seems that the women were told to exclusively breastfeed at the clinic, but many stopped breastfeeding anyway because they were still afraid of passing the virus to their child. If they had continued breastfeeding as recommended, they would not have faced stigma in the community. I realize this has to do with the mixed messages about HIV and breastfeeding over recent years in Kenya and similar countries, but it may be difficult for someone who does not know that context to understand. Perhaps a few sentences at the beginning of this section could clarify this (there is now a paragraph in the discussion).

17. Section 3.2.2, Page 14: For the quote at the top of page 14, it would be helpful to include more of what the woman said, so that we can understand what she meant. The interpretation given above the quote by the authors seems much broader than what the woman said in the quote.

18. Section 3.2.3, Page 14: It is unclear why the ARV adherence information is only given for the PNC respondents, not the FP respondents.

19. Section 3.2.3, Page 15: It is indeed interesting that women report that stigma does not impede their ART adherence. However, the authors should acknowledge that this is what the women chose to report to the interviewer, and we do not know anything about their actual adherence. This may also be a selected sample, not including those who struggle most with stigma and adherence.

20. Section 3.3, Pages 15-17: This section on health information and support
groups seemed to be the weakest part of the paper. Most of it did not have much
to do with stigma and discrimination. The last quotation, for example, is about
having correct information about PMTCT, and doesn’t say anything about stigma.
I think this section of the paper could be shortened and it would be improved if
the authors could present more data supporting their claim that these support
groups and health talks help reduce internalized stigma. Internalized stigma
could then also be added to the types of stigma examined in the article.

Discussion:
21. Page 17: It would be better if the authors could use more tentative language
(e.g., appears, suggests, women reported) when talking about stigma not being a
barrier to adherence. Again, this study does not have any data on actual ART
adherence, just what the women chose to tell the interviewers.
22. Page 18: Although the paragraph on breastfeeding is helpful in making sense
of the findings, there is still a lack of clarity. It seems like fears of stigma would
lead women to continue to breastfeed, whereas fears of transmission to the baby
would lead them to stop breastfeeding. Yet the 3rd sentence in the first
paragraph on this page seems to indicate that both of these would lead to early
cessation of breastfeeding.
23. A limitations paragraph is needed, stating any potential effects of the
sampling strategy on the types of women who participated, and any other
limitations or caveats of the study. If no specific measures were taken to verify
the findings (e.g., triangulation, member checks, peer debriefing, etc.) then that
would be another limitation. Analysis in English could also mean that some
meanings were lost in translation.

Conclusions:
24. Page 20: Again, I would suggest more tentative language regarding the
finding that women “overwhelmingly” overcame stigma to adhere to their drugs.

Tables:
25. Page 25: Could the authors also include data on type of marriage
(polygamous vs. monogamous)? This has been found to be an important
determinant of fearing and experiencing stigma among pregnant women in
Kenya. (See References 1 & 2 below.)

Minor essential revisions:

Abstract:
26. Results: The sentence referring to a “link between HIV support groups and
high self-worth” could be more clear. Do the authors mean that attending support
groups leads to increased self-worth among HIV-positive women?

Results:
27. Section 3.1, Page 8: What does “Engineer-control” mean in the quotation
identifier?
28. Section 3.2.1, Page 10: “More than half of the women in the study disclosed their HIV positive status only to their close family for fear of negative beliefs about people living with HIV.” Was this for fear of the beliefs or for fear of resulting stigma and discrimination?

29. Section 3.2.1, Page 10: It would be interesting to know who are the “close family members” to whom women did disclose their HIV status.

30. Throughout: If the quotations were translated from Kiswahili, I am unclear why the English seems incorrect in some places, since these are not direct quotes. For example, in the quote on page 13 “why have you kept it a secret to them....”.

References:


Level of interest: An article of importance in its field

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.