Author’s response to reviews

Title: Challenges faced by caregivers of virally non-suppressed children on the intensive adherence counselling program in Uganda. A qualitative study

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Response to Reviewers

Please note that the indicated pages and line numbers are consistent when the view is in simple mark up.

Reviewer One

General Comments This study explored the challenges and modes of support that caregivers need to help children achieve adherence and viral suppression. This study important considering the poor level of adherence among children. While the manuscript is generally well written, I have some suggestion on ways of making the manuscript even better.

Response: Thank you for reviewing the manuscript. I have addressed the suggestions in the sections below and hope that the manuscript is now much better.
First, authors should review studies on challenges caregivers face in supporting virally non-suppressed children and summarise the findings in the background. Perhaps, studies on challenges faced by the caregiver of children living with HIV, in general, could provide the needed background for this study. It is important that this study builds on the existing body of knowledge. This could make the background better.

Response: Studies that are specific to virally non-suppressed children were not found. However, studies that highlight challenges in caring for an HIV positive child have been added in the introduction. We believe this has made the introduction stronger as proposed. See Introduction section, page 5 lines 131 to 135

Line3-9 of page 5: What were the reported reasons for the poor adherence found in the study? How long was the programme and could adherence be achieve given the duration of the sessions?

Response: The original study was a quantitative study that showed that only 77% of the children actually go through the IAC program as envisioned by the government of Uganda. (This is the low adherence to the program that was mentioned, not adherence to medication). This work was published and is referenced (reference number 26).

Since the quantitative findings could not adequately answer the question why there was low adherence to the recommendations, this quantitative study was designed. In this paper, we explored the challenges caregivers face in going through the program. The results are reported in table II. These could explain the low adherence to the guidelines.

The IAC program lasts between 3 months and 6 months, with at least 3 contact visits for adherence support. This has been clarified in the introduction on page 5, line 143. It is hoped that given the program runs for months, a child and caregiver will have time to improve adherence to medication and hence improve viral suppression.

Methods What is phone consent? I don't think I have ever heard that term?

Response: This refers to verbal consent on phone, which was followed by written informed consent to participate. Participants were called on the phone and asked if they were interested in participating in the study, those that showed interest were invited to the facility where written informed consent was obtained prior to the interview. The section has been reworded to clarify this point. See methods section: Participant selection page 7 lines 174 to 177.
Authors wrote that the FDG were obtained in both English and local language. However, they did not write about how the data were translated into English. Also, how did they ensure the accuracy of the translation?

Response: More information about the translation has been added to the text to show that a translator did the translations and they were checked by another fluent speaker. See Methods section, pages 7 to 8, lines 192-193.

Lastly, the authors stated that their findings were also compared with results from similar studies. Line 51, page 6. Which studies are they referring to? Perhaps they could reference those studies.

The studies that show caregiver challenges in general have been referenced. See methods section, page 8, line 206

Results In places where authors reference Tables and Figures, their spelling began with small letters. It should be written as Table 1, Table 2, Figure 1, Figure 2.....etc.

This has been changed. See results section page 8 line 179, page 9 line 190, page 10 line 219 and page 13 line 285

Line 1 of page 11, the first "the" should be deleted.

This section has been removed as the results were re-written to make them better.

Overall, the analysis of findings is not focused and detailed enough. Rather than listing many themes, an attempt should be made at grouping this themes in a more concise way. It is difficult to follow the result because of many headings. Authors should use the result to tell a story that interesting to readers.
An attempt to decrease the number of headings has been made. In the challenges section, only five headings corresponding to the major themes have been left highlighted. The information in table II has been summarised to make it less tedious and more interesting to the reader.

Figure 1 has also been revised to provide more information on the sub-themes so that the text can be reduced. We hope that the results are now easier to follow.

See results section, pages 8 line 188 to page 13 line 331

Discussion: The discussion is overall good. However, the fact that the findings are not generalizable should be stated in the study limitations.

This has been added to the study limitations. See page 17 line 398.

Table 2: quote should be removed from the table. I supposed authors would have discussed this theme and subthemes in the result and reference these quotes.

All the quotes have been removed from table II. The findings from table II have been summarised in the text and the relevant quotes referenced just below the summary. See methods section pages 9 to 10 lines 195-214

Reviewer Two

Thank you for an interesting paper. Overall the study methodology is well described. However the results and the tables/figures need to be revised to ensure consistency.

Thank you for reviewing the paper and for the helpful comments and suggestions. The results, tables and figures have been revised to ensure consistency.
See results section, pages 8 line 188 to page 13 line 331 figure II and table II edits.

The paper suggested that there will be two main questions: one on the challenges and another on what caregivers like to have improvements on.

We set out to determine the challenges caregivers face in helping children to adhere and any improvements they want to see that will make viral suppression a reality for their children.

Three major themes were reported in the abstract: 1) Health system reforms; the caregivers called for clinic times outside of school hours, reduction in stock outs of paediatric ART regimens and improved quality of counselling. 2) Psycho social support; they requested for support for disclosure to their children and families, more frequent peer support groups and parenting classes. 3) Economic empowerment; Lack of money was a major stumbling block and requested to be trained in vocational skills, help with school fees and support to start up income-generating activities to make some money to support the children.

This was an oversight on our part when results to only one question were reported in the abstract. We apologize. The results section of the abstract has been rewritten to show all the results to the two questions. See abstract under results section, pages 3 to 4 lines 91 to 104.

The mentioned themes emerged as an answer to the second question. (What changes would caregivers like to see in order to help them better support their children). This has been clarified in the abstract on page 3 line 89.

The themes that emerged in answer to the first question have been included in the abstract under results.

However the results were not consistent as in the text it were different: 1. In the text Five major themes were cited to have emerged as the challenges to improvement in adherence (figure 1).
This is true, these five themes were in answer to the first question. What challenges do caregivers face in trying to improve viral suppression for their children? They did not answer the second question. See abstract under results section, pages 3 to 4 lines 91 to 104.

There were no sub themes in the figure although it was included in the text. Quotes were included to support the sub themes - however there was no information whether it was elicited from biological mothers/relatives/siblings which would have given the contextual explanations to it.

The sub themes have been included in figure 1. See attached edited figure 1.

Information on the person that made the statement has been added to the quotes in this section. See page 10 lines 225, 227, 231, 262; page 11 lines 238, 244, 251, 254, 258; page 12 lines 260, 269, 278, 280,

2. There were three more themes cited in the text for Support that the caregivers would like to receive in order to help the children suppress their HIV viral load (Figure II) which did not have any illustrative quotes to support the three themes. Relevant quotes need to be included to provide the support for the themes identification 3.

The quotes have been included in the text to support the themes and sub themes that emerged as the support that caregivers need to help children suppress the viral load. See pages 13 to 14 lines 291, 297, 305, 314, 322, 329.

It was mentioned that a guide with open ended questions and an allowance for probing questions, was used to moderate the discussion and that this guide had four thematic areas that explored the challenges caregivers faced - please include details about the interview guide questions to ensure its relevancy and comprehensiveness.

The kind of questions that were asked are clarified on page 6 lines 155 to 157.
The interview guide has been uploaded as one of the supplemental materials for the study.

It was mentioned that Five FGDS were held although saturation of data was achieved after four FGDS How was data saturation ensured?

After 4 FGDS, there was no more new information coming out of the discussions. The caregivers were mentioning the same factors. This is how saturation was ensured. However, the fifth FGD was held anyway to confirm that saturation had indeed been reached. This has been removed from the methods section.

3. Discussion was only focusing on what was reported in the literature. It could be improved with discussing it against the societal, cultural and economical situation 4.

A paragraph showing the current situation in Uganda has been added to the discussion.

See page 17, lines 384 to 390

4. It was noted that there was a 15-25 years old category - how was the consent taken for those below 18?

There was one caregiver below 18, a 17 year old girl. The other 3 were above 18 but below 25 years of age. She was an emancipated minor as she is the head of the home where her HIV positive brother resides. Due to this status, she was able to give informed consent on her own behalf. This has been clarified in the methods section on page 6 lines 146 to 149.