Author's response to reviews

Title: 'Pregnancy comes accidentally - like it did with me': Reproductive Decisions among Women on ART and their Partners in Rural Uganda: A Qualitative Study

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Author's response to reviews: see over
Dear Editor and Reviewers,

We thank all five reviewers for their insightful comments that we think have substantially improved our manuscript. Please find below a point-by-point response to each comment. To ease the reading of our responses, we have copied and pasted each comment and added the response below it in a distinct font, and we have inserted line numbering on each page of the revised manuscript and referred to the new page and line numbers (in track changes version) in our responses here.

Thank you again for your kind consideration.

With best wishes,

Rachel King

Reviewer 1 - Jolly Beyeza

INTRODUCTION

1. Second paragraph lines 1-2 needs a citation for the source of the information. “Reproductive decision-making for HIV-infected men and women encompasses a complex web of biomedical, cultural, and socio-economic factors.”

   • We have inserted appropriate references (line 20; page 1)

2. The role of the health care provider is key in shaping and coloring access to reproductive health services [9]. The use of colouring is superfluous and journalistic. It may not be suitable for scholarly writing.

   • We have ended up deleting the sentence where the word ‘colouring’ was found in the revised version of the manuscript (lines 22-23; page 1)

METHODS

3. We conducted a qualitative sub-study with participants enrolled in the Home-based AIDS Care project (HBAC) in rural Eastern Uganda [13]. When was this study conducted? How long had they been in general TASO care? How about in HBAC care?

   • We have added the dates for the sub-study (line 17; page 4) and the dates for enrolment in the parent HBAC study (line 1 page 5). Participation was on-going so there was no termination.

4. Research counsellors visited participants quarterly to collect behavioral data, and to provide ongoing support on adherence to ART and on sexual behavior risks though they didn’t particularly emphasize family planning And
Page 4, first paragraph lines 8-11. In addition, study participants were counseled at enrolment about the potential effects of ART on restoring health, fertility and sexual activity, and were referred to the hospital family planning (FP) clinic adjacent to the study clinic if interested in using FP other than condoms. These two statements are contradictory and should be sorted out. It is not clear whether they later started giving FP counseling (because fertility counseling includes FP) or how they chose who to refer to hospital for FP (since they were not counseling about FP).

- The first sentence was changed so as not to contradict the second sentence, as follows:

  “Research counselors visited participants quarterly to collect behavioral data, and to provide ongoing support on adherence to ART and sexual risk behavior.” (lines 10-11; page 5)

5. The FP clinic provided standard FP counseling and services including any number of clinic visits and contraceptive methods.

I have read this sentence several times and I seem to get no meaning. May be “including any number of clinic visits” is misplaced.

- The sentence on lines 5-9, page 6, has been re-written to read:

  “The FP clinic provided standard FP counseling and FP services including as many clinic visits as necessary. Contraceptives were supplied by the Ministry of Health and included combined oral and progesterone-only pills, hormonal injectables and implants, intra-uterine devices and tubal ligation and condoms.”

6. A quantitative analysis of cohort data found high rates of unintended pregnancy among…. “THE” is missing between of and cohort.

- The sentence has been modified and moved to the introduction on page 4, lines 2-5, as suggested by reviewer 2 (Landon Myer). It now reads as follows:

  “We previously reported low desire for children and high rates of unintended pregnancy in a prospective cohort study of 718 HIV-infected women followed-up for 24 months after ART initiation in rural Uganda”

7. After reading two transcripts, the analysis team members collaboratively developed a codebook of themes based on the interview topics as well as those emerging from the data. Two more transcripts were then reviewed to include additional topic areas and themes. This process was repeated until the codebook reached a stage where no new themes or topic areas emerged. (Which process are you alluding to? Of taking two more scripts at a time for reviewing? How many scripts did you review to reach final version of the codebook, to start coding all transcripts?)

- This process is called ‘thematic analysis’ as described by Boyatzis, 1998. At each stage, 2 new transcripts were reviewed. The entire process was repeated five times until the
codebook reached a stage where no new themes or topic areas emerged. Thus a total of 10 transcripts were reviewed by the coding team (lines 15-21; page 7).

RESULTS

8. Eighty-five percent of the women who were pregnant, aborted or had delivered recently. It is difficult presenting qualitative research in figures and percentages. What seems to dominate qualitative research are rather the themes and concepts, experiences and etc.
   • The percentage has been changed to actual numbers of participants as suggested by reviewer 5 (Diane Cooper) (lines 1-2; page 9)

9. More women (11) than men (2) cited partner’s desire for children as an important factor associated with pregnancy. Again in qualitative research, the numbers stop being important. After all, you counted them and got the percentages in the cohort study mentioned in the text before.
   • The numbers have been removed (line 17; page 9)

DISCUSSION

10. In Uganda, ART initiation counselling is packed with information focusing on adherence and assessing an individual’s readiness to start a life-long treatment. Individuals are often very sick and may be over-whelmed with the amount of information. This may not be the ideal time to address issues of changing fertility and family planning options.
True it is not ideal to initiate counseling for FP and options at the initiation of ART. However, these patients have been followed up for a long time, (Though the study does not tell us when recruitment into HBAC started). In addition, the patients have been in TASO care for sometime even before HBAC started. The authors should discuss this critical gap in patient care of this cohort as one of the reasons for high unmet need for contraception and especially the high rates of unintended pregnancies.

   • Two sentences were added to mention the identified gap in long-term care services for HIV infected individuals.

   This study has thus identified a critical gap in reproductive health services for individuals in ART care. Family planning counseling and methods should be offered regularly and systematically to patients on ART throughout follow-up and more specifically in the first months following initiation of ART as they get better and are most likely to resume sexual activity (lines 15-19 page 20).

11. The citation needs to be harmonized to one style.

   • The references have been cleaned up; all adhere to the style of the journal.
12. She is using Depo injection and she has used it for almost one year now. Before she started using it, she was fat and now as she is using it, she has started losing weight. (Man with 1 living child, 4 deceased, delivered)

   This is a strange finding in African/Ugandan men. Besides the little appreciation for slim women, losing weight when one has HIV infection is rarely regarded as good

   • This participant was mentioning that the use of injection had been effective in preventing childbirth. The weight issue may not be related. We have left it as it is.

Reviewer 2 – Landon Myer

INTRODUCTION

1. Overall – the intro covers the necessary issues but is not well structured into a coherent flow. Some reworking is needed here.
   • We have re-structured and completely re-written the introduction to improve the flow.

2. The sentences referring to Kaida, Hladik, Myer. These references are important, but how they relate back to the point that the authors is trying to make is a bit unclear.
   • We have explained the relationship between the references and the points we are trying to make in the revised introduction.

3. Third para of introduction – this is strangely situated – a 1 sentence para that is not clearly linked to what comes before or after - and should be folded in elsewhere
   • As stated in point 1 – we have completely re-written the introduction

4. “complex web” is overused in the manuscript.
   • We have reworded the sentences where this phrase was repeated so that it is now used only once in the entire manuscript.

METHODS

1. The 1-sentence para, “A quantitative analysis…..” Really belongs in the introduction, not the methods
   • We have removed this sentence in methods, reworded it (see response to comment 6, reviewer 1 above) and added it to the revised introduction (lines 2-5, page 3).
2. The end of the introduction suggests that this is a partner study – but only some women had partners enrolled. This should be clarified in the intro, and the sampling of male partners needs clarification. Was there an attempt to identify all women’s partners, and these were the ones who agreed to participate?

- We have clarified the numbers of partners as follows:

  “Counselors attempted to locate all partners of women selected for the study, but not all women had partners able to participate. The 16 male partners interviewed were those who not only agreed to participate; but also were in an ongoing and/or stable relationship with their partners; and were available for the interviews” (lines 3-6; page 7).

RESULTS

3. The analysis contains several inappropriate quantifications – calculating percentage participants who said different things should be avoided in this kind of method.

- We have removed quantifications as suggested by Dr Myer and other reviewers

4. The subheadings need work. “Emotional/personal” needs rephrasing eg, “emotional and personal reasons”. Is “Lack of family planning” a subheading under “Practical/structural” or was text accidentally deleted?

- We have rephrased the subheadings as: “Emotional and personal reasons for pregnancy” and “Practical and structural reasons for pregnancy” (line 16 page 9 and line 2 page 11)

5. Figures 1 and 2 look like power point slides and need to be reworked into black and white line drawings prior to publication

- We have reworked the figures 1 & 2 into line drawings

6. The use of boldface font should be avoided.

- We have removed all bolded words except for the subheadings with the view that the editors will modify this as required during the editing process

DISCUSSION

- The limitations heading has been removed as suggested

1. The first sentence of the limitations sections does not make sense. This is a qualitative study (cross sectional is a term generally for quantitative studies) –
and this study could assess, in a qualitative way, the strength of different motivations.

• The first sentence of the limitations has been reworded as

“This analysis was not without limitations. It was intended to identify influences on reproductive decisions; however as a qualitative study, we could not determine the strength of individual motivations for pregnancy” (lines 22-24; page 20).

• The reference to table 2 in the final paragraph was deleted.

Reviewer 3 – Pranlee Liamputtong

1. The paper is too 'descriptive' and it does not add any new knowledge to the field.

• This paper intends to describe, using qualitative methods, the factors at play in reproductive decision-making among couples with the woman on ART in rural Uganda. To our knowledge, there is little qualitative information in the literature that explores the influences at play on HIV-infected couples’ reproductive decision-making in the context of ART. The fact that most of our findings confirm previous observations by others in different populations and contexts could not be anticipated and does not, in our view, reduce the importance of this study for the population concerned (women on ART and partners). We would also like to point out that the 3 other reviewers highlighted the importance of this study to the field.

2. The paper is not based on any conceptual framework. It renders the paper conceptually weak. In a qualitative study, the findings should be situated within some conceptual frameworks or to develop some conceptual frameworks from the data.

• We have included the conceptual framework that we were using during the design of this project as a figure (Figure 3). However, we leave it to the editors to decide whether or not this is an important addition to the paper.

3. However, the authors report their findings as if it is a quantitative research using numbers to indicate how many participants subscribe to each issue. This is inappropriate and inadequate for a good piece of qualitative research.

• As also suggested by other reviewers, we have deleted the numbers and focused on the emerging concepts.

Reviewer 4 – Gail Hawkes

This is an excellent small study of an important dimension of preventative sexual health. It is clearly introduced and good use is made of the qualitative data. My only suggestions might be to develop some more insights into the 'hearts and minds' of the participants from the data in order to strengthen the impact of the findings on future
health education policy. Nevertheless, as someone who teaches qualitative methods to undergraduates, I would be happy to use this as an example of a well-thought out and executed study.

- We have taken another critical look at the raw data to try and reflect more deeply on the lives of participants described in each transcript. We have included more quotes in order to convey a deeper reflection of the ‘hearts and minds’ of participants.

Reviewer 5 - Diane Cooper

INTRODUCTION

1. There are some further articles that could be included.
   - We have included Dr Jolly Beyeza’s articles (2009, 2010), Cooper et al 2009, Myer at al (2007, 2010), Kaida et al. (2006) (line 10; page 1, line 5; page 2, line 22; page 3 and line 16; page 18).

METHODS

2. Can the authors explain the significance to this study of the clients being randomized to three different monitoring strategies and explain briefly what this was about.
   - We have deleted the second half of the sentence which mentions the 3 different monitoring strategies, since, as the reviewer correctly pointed out, there is no significant relevance to this sub-study (lines 5-6; page 5).

RESULTS

3. In paragraph 1 on page 6, final paragraph: It is the only time the authors use % for the themes (it is appropriate to use this in the sample characteristics). There is some controversy over whether this is appropriate in qualitative research. I prefer not to, but rather to talk in terms of numbers or many or few as the authors do in the remaining results.
   - We have changed the percentage to numbers at the reviewers suggestion (line 1; page 9)

4. More Quotations: I realize that the authors have a problem of word limit but it would be worth giving a few more quotations to illustrate themes emerging as this is how the data is shown in qualitative research. Even if they are truncated quotations. For e.g. the following themes: financial dependence of women (did financial issues emerge at all for men in a different way? The need to sustain a family etc?).
   - We have added 5 quotes in various places to illustrate the themes more in-depth as follows: Lines 12-13; page 11 – by a woman discussing her new partner
   - Lines 16-21; page 13 & lines 21-23 page 15 – man on financial situation first one as motivation for and the second one motivation against pregnancy
5. Given that this is an article about people living with HIV on ARV’s did being on ARVs not come up as an issue as it has in other studies
   - The reviewer rightly noted that we had no analysis related to ART in the results. Originally, we had included an entire section of the results and discussion on that topic but we felt it made this paper too long. However, with the encouragement from this reviewer, we have included a smaller sub-section on ART in the results and discussion sections of the revised manuscript (lines 1-19; page 16).

6. The authors mention that for the most part there weren’t gender differences – this is also somewhat surprising. For e.g. did men not men finances at all; what other issues? Could they tease this out a bit more.
   - The reviewer asked to tease out more clearly the gender differences in analyzing participants’ responses about their reasons for pregnancy. We have added to the manuscript a more detailed explanation and some additional data regarding gender issues:
     
     The motivations in each category were often mentioned by both men and women though at times, the way in which the idea was expressed was different or some issues were expressed more frequently by either men or women. There were, in addition, a few gender-specific explanations.
     
     lines 11-14; page 9 and lines 16-21 page 13:
     
     “I really wanted her to get pregnant because I felt I wanted to try and have a child who would be negative. I felt the pressure within myself that I should have a child so that when I die he could take over my estates. You first look at your state especially us on ARVs, are you able to look after the child after breastfeeding. One needs to look at the economic base before you make the decision” (man).

7. Did issues of leaving children as orphans that have arisen in other studies not emerge at all? Was this not asked about?
   - In response to the reviewer’s questions about the issue of leaving children as orphans; we re-read the raw data on men’s and women’s responses about ‘reasons not to have children’, and found that many participants mentioned ‘ill health’ which is definitely related to leaving orphans but interestingly ‘leaving orphans’, stated directly was not mentioned as such.

DISCUSSION
8. The authors should discuss some issues analytically in more detail. For e.g. Given that according to Table 1 such a high percentage of respondents had lost a child this should be commented on more as a potential issue either driving fertility intentions or militating against them.

- These quotes are in the results:

  p. ...: “Given the fact I had lost all my children, I didn’t want to grieve again” (woman who lost 4 children, not pregnant)

  p. ...: [... ] I kept thinking about the miscarriage I had before; the pain I went through. I wondered how I would be this time. Life became so miserable ... I felt like committing an abortion or even dying. I kept thinking that even if the child lived, it would live a desperate life because it will also suffer like I have suffered. (woman with 1 living child; 3 deceased; aborted)

In the discussion section death of a child is discussed on lines 17-19 on page 19;

“Death of a child served to motivate couples to either replace lost children, or to adopt stricter family planning practices in reaction to the grieving process that was extremely painful for many.”

9. The authors should refer to other studies that either support or are different to their findings more: e.g. Pregnancy being associated with a younger age (Cooper et al, 2009); knowledge of PMTCT; financial issues; the complexity of decision-making etc.

- We have added two sentences:

  - Pregnancy desire among HIV-infected women has been positively associated with younger age, and knowledge of PMTCT in South Africa and Uganda [2,30] as well as with male gender, having fewer children, living in informal settlements and use of HAART in Cape Town, South Africa [31] (lines 13-16; page 18)

  - These findings echo what others have found in similar situations and underscore the complexity of the determinants of decisions and non-decisions{Cooper, 2009 #95}. (lines 2-4; page 19)

10. More data should be presented in the form of quotations on the participants concerns on a link between pregnancy, having children and deterioration in health status as this is a similar finding militating against childbearing in other studies.
We have added the following quote:

“It is because when they first tested my CD4 they said I was weak. If I am to give birth, I don’t know what I will give birth to [will it live?]. Besides, whom am I giving birth for? I want my children to reach a certain level. If I am to think about the last child I had, I did not know I would live to date? It’s a miracle. That is why I do not want to have another child or even talk about it (non pregnant woman with 4 living and 1 deceased children).

11. Page 12, paragraph: Can the authors give the readers an idea of what participants were counselled about by health care providers, as providers discouraging pregnancy is an issue that has come up in numerous other studies.

- The details of the counseling provided to clients is presented in the methods as follows:

Page 5, lines 18-23 and continued on page 6, lines 1-6:

Prior to HBAC, advice and counselling had been given by TASO on condom use as well as on abstinence as the most effective HIV transmission prevention strategies for sexually active persons. On joining HBAC, participants were provided again with information detailing a range of HIV risk reduction options including condom use, abstinence, partner testing, disclosure of HIV status to current or new/potential sexual partners, being faithful to one HIV-tested partner, reducing the number of sexual partners, reduced frequency of sex, alternative forms of sexual expression, and treatment of STIs. In addition, study participants were counseled at enrolment about the potential effects of ART on restoring health, fertility and sexual activity, and were referred to the hospital family planning (FP) clinic adjacent to the study clinic if interested in using FP other than condoms. The FP clinic provided standard FP counseling and FP services including as many clinic visits as necessary.

lines 6-9; page 20:

In Uganda, ART initiation counselling is packed with information on HIV sero-status disclosure and discordance, ART drug adherence and potential side effects as well as family planning.

12. Limitation. As this was a qualitative study, it could not determine the strength of the motivations for pregnancy. This is not because it was cross-sectional.

- This sentence has been corrected as: [...] however, as a qualitative study we could not determine the strength of individual motivations for pregnancy. (lines 22-24; page 20,)

13. Page 13, paragraph 3: the authors made good points about counselling etc. and this could be linked more to presenting some results on this in the results section.

- We have included a sentence that links back to the point of family planning as,
Our study found that both men and women wished to use more permanent methods after their counselor explained the benefits of these methods. The quotes on family planning are reported in Table 2.