Author’s response to reviews

Title: HIV status disclosure and associated outcomes among pregnant women enrolled in antiretroviral therapy in Uganda: a mixed methods study

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Version: 3 Date: 02 Mar 2017

Author’s response to reviews:

February 28th, 2017

Dear Editor,

Manuscript No: REPH-D-16-00017

‘‘HIV status disclosure and associated outcomes among HIV positive pregnant women enrolled in antiretroviral therapy in Uganda: a mixed methods study’’

Thank you for giving us an opportunity to revise and resubmit our manuscript. We have made revisions in line with all the comments that we received. Below is a point-by-point response to all the comments.

Sincerely,

Rose Naigino
1.0 Abstract

1.1 Remove abbreviations from abstract

All abbreviations have been removed from the abstract - see page 2 and 3 of the manuscript with track changes.

1.2 Disclosure of HIV positive sero-status is encouraged by prevention of mother-to-child transmission (PMTCT) programs to enhance outcomes.

This is not clear, replace with specific objectives. This statement has been rephrased for clarity. The revised statement reads:

Disclosure of HIV positive status to sexual partners is promoted by HIV prevention programs including prevention of mother-to-child transmission (PMTCT) to among other benefits enhance spousal support and reduce HIV-related negative outcomes such as stigma, violence and discrimination. We assessed HIV status disclosure and associated outcomes among a cohort of women newly initiating lifelong antiretroviral therapy in Uganda between October 2013 and May 2014. (See page 2 of the manuscript with track changes)

1.3 PMTCT programs in the context of high levels of stigma, discrimination and violence should integrate interventions to reduce negative outcomes.

To reduce what sort of negative outcomes?

This statement has been rephrased for clarity.

The revised statement reads:

HIV status disclosure to sexual partners by mothers on lifelong antiretroviral therapy was associated with increased spousal support but was impeded by stigma and fear of adverse outcomes such as stigma, discrimination and violence. PMTCT programs should integrate interventions that address these adverse outcomes to promote disclosure among mothers. (see page 3 of the manuscript with track changes)
2.0 Plain English Summary

2.1 Over 80% of the women who had sexual partners reported receipt of spousal support, especially those who disclosed to their spouses.

If they are pregnant don’t they all have pregnant partners by definition?

The question was focusing on women who reported being married and so reported having a husband/spouse as determined by the women themselves.

This statement has been revised as stated below.

(see page 4 of the manuscript with track changes)

Four-in-five women (81.1%) who were married at the time of the interview received spousal support.

3.0 Background

3.1 Out of a total of 1,493,164 pregnant women who were tested and received results during ANC, 8% (122,753) were found to be HIV positive. Define abbreviations upon first use. The word ‘ANC’ has been replaced with ‘antenatal care’.

We have also maintained the abbreviation ‘ANC’ for antenatal care in brackets for reference in other sections of the manuscript. (see page 5)

A study done in Kenya among HIV positive mothers showed that women living with HIV who had not disclosed to anyone had the lowest levels of PMTCT service utilization. Is this fertility rate?

The word ‘maternity’ has been deleted to make this statement clear. The revised statement reads:

A study done in Kenya among HIV positive mothers showed that women living with HIV who had not disclosed to anyone had the lowest levels of PMTCT service utilization. (see page 5 of the manuscript with track changes)
4.0 Methods (The results are quite lengthy and many sections are repeated, I suggest review to make this more concise)

4.1 The models of PMTCT services also varied across health facilities (Table 6) All tables should be listed and in order.

This has been addressed. All tables are now listed in order across the entire manuscript.

4.2 Data collection methods

Quantitative interviews

Was this a written survey? ‘quantitative interview’ seems to be a contradiction  The two subheadings under this section: ‘Quantitative interviews’ and ‘Qualitative interviews’ have been removed.

This section on data collection methods has been revised to make it concise.

(See page 10 of the manuscript with track changes)

4.3 The restriction to the first two follow-ups was as a result of available data at the time of conducting this data analysis. This is not clear

This statement has been deleted for clarity purposes. (See page 10)

5.0 Results

Socio-demographic and clinical characteristics

5.1 The mean (SD) age was 25.1 years (SD=6.2), 262 (51.3%) women had completed primary school and 406 (80%) were married. This is not particularly informative, with un-skewed data this is expected since the mean is 25
We have maintained this statement as part of a standard way for reporting distribution of unskewed data which includes reporting the mean and the corresponding SD. (See page 15 of the manuscript with track changes).

5.2. Among women with partners, 47.9% (n=195) reported their partners had been tested for HIV. The reported HIV prevalence was 42.3% (n=82) at the first follow-up visit (2 months post-enrolment) and 46.7% (n=86) at the second follow-up visit (4 months post-enrolment). Please revert if I misunderstood the message here. It was not clear to me what was the rate of partners’ testing and self-reported rate of testing

This statement has been rephrased to make it clear and concise.

Suggestion

Nearly half (47.5%, 195) of the women reported that their partners had tested for HIV. Women reported that 42.3% and 46.7% of partners as HIV-positive at the 2 and 4 months follow-up, respectively. (See page 15 of the manuscript with track changes)

5.3 Disclosure of HIV sero-status

It does not seem required to indicate ‘sero-status’ in most cases, it may be more concise if simply ‘HIV status’ were used.

Across the entire document, all words indicating ‘HIV sero-status’ have been replaced with ‘HIV status’. (See page 16 of the manuscript with track changes)

5.4 Disclosure was highest in Masaka hospital; 82% at FUP1 and 88.8% at FUP2, followed by Mityana hospital; 79.7% at FUP1 and 83.9% at FUP2, and lowest at Luwero HC/IV; 64% at FUP1 and 77.0% at FUP2 (Table 2).

64.0%? Use consistent number of decimal points to ease comparison between groups

One decimal point has been maintained in all proportions across the entire document.
5.5 At both follow up visits (FUP1 and FUP2), women most commonly disclosed to their spouses \([353 (59.5%), \ 374 (58.0%)]\), followed by sisters \([353 (36.8%), \ 373 (42.1%)]\) and mothers \([302 (37.7%), \ 330 (39.4%)]\) (Table 2).

Do you have any information regarding those that disclosed to multiple people?

Yes, refer to Table 2 for details on the proportions of women who disclosed to multiple people. The statement below has been added to include information on the percent of women who disclosed to multiple individuals.

'At visit 2 (4 months post enrolment) only 11 (2.9%) had not disclosed, 187 (49.6%) disclosed to one person while 179 (47.5%) reported disclosing to at least two persons'.

5.6 Support for adherence to ART was present among many who disclosed their status. Was this also spousal support or support by anyone?

This was specifically spousal support which was assessed in the form of telephone reminders to take their medication on time, accompaniment to retrieve their medications.

For clarity, the word ‘spousal’ has been added at the beginning of this statement. (see page 17)

5.7 This type of support included being accompanied to retrieve their medications \([n=19 (8.4%), \ n=14 (10.6%)]\) and reminders to take their medication on time \([n=226 (85.3%), \ n=132 (46.3%)]\)

This is one of the first indication of support decreasing at FUP2, this may deserve mention or further discussion. So why do we see reminders to take medication decreasing at the 4th month? Could this be that someone is now used and up to speed with adherence, which is known to improve over time? The finding has been further discussed on page 24 as indicated below.

Spousal support decreased by the 4th month post-enrolment. Duration on ART is known to be associated with higher adherence levels among women living with HIV. Spousal reminders in the first 2 months of ART treatment may enhance ART adherence among women. Therefore by the 4th month, the need for a reminder may be limited once adherence has picked up.
5.8 Spousal support was higher among women who had disclosed to their spouses \( [n=265 \ (80.3\%)] \) at FUP1 and \( n=285 \ (89.0\%) \) at FUP2 than those who had not disclosed \( [n=65 \ (19.6\%)] \) at FUP1 and \( n=35 \ (10.9\%) \) at FUP2 (Table 3). Is this truly informative, how could one receive spousal support for HV if they were not aware of their spouse’s + status?

We have maintained this statement because spousal support was not only for HIV but included support for non-HIV specific services. The statement below has been added for clarity.

Spousal support included support for non-HIV specific services for instance being escorted to antenatal or postnatal care was not necessarily based on one’s disclosure status. (See page 17 of the manuscript with track changes)

HIV-related stigma, discrimination or violence

5.9 Few HIV positive women reported stigmatization \( [n=35 \ (7.6\%)] \), discrimination \( [n=25 \ (5.4\%)] \) and violence \( [n=18 \ (3.9\%)] \) at the first and second follow up \( [49(10.8\%), \ 24(5.3\%), \ 17(3.7\%)] \) respectively (Table 2).

Should this be ‘or’? Did 3.9% experience stigma, discrimination AND violence? If so, you should also consider including the independent rates of each negative outcome.

The 3.9% experienced only violence.

Below is the suggested re-working for clarity of results (see page 20 of the manuscript with track changes)

Comparing follow-up at month 2 and 4, the percent of women who reported ever experiencing stigma \( [35(7.6\%) \ vs \ 49(10.8\%)] \), or discrimination \( [25 \ (5.4\%) \ vs \ 24(5.3\%)] \) or violence \( [18(3.9\%) \ vs \ 17(3.7\%)] \) were similar.

Table 5 shows the association between negative events (such as HIV-related stigma, discrimination or violence) as the main dependent variable, and HIV sero-status disclosure to at least one person (main independent variable) adjusting for age, education level, marital status, employment status, type of visit, enrolment health facility and alcohol/drug use. In the adjusted
analysis, the risk of HIV-related negative events was 11% lower among women who had disclosed than those who did not; after adjusting for age, occupation, type of visit and alcohol/drug use (adj.PRR=0.89; 95%CI: 0.56-1.42) (Table 5). The prevalence of HIV-related negative events was 16% higher in Luwero than Mityana (adj.PRR=1.16; 95%CI: 0.66-2.02), almost 3-fold higher in Masaka (adj.PRR=2.25; 95%CI: 1.44-3.52) and much lower among married women (adj.PRR=0.56; 95%CI: 0.34-0.91) than the never married (Table 5). Are all of these results significant? Many of the ratios cross 1 and have wide confidence intervals. Yes, we agree. Not all these associations are significant.

Below is the suggested re-working for clarity of results (see page 21 of the manuscript with track changes)

Table 5 shows the association between the self-reported adverse events (HIV-related stigma, discrimination or violence) and HIV sero-status disclosure to at least one person adjusting for women’s age, education level, marital status, employment status, type of visit, enrollment health facility and alcohol/drug use. In the adjusted analysis, the risk of self-reported adverse events was significantly lower among married compared to never married, adj.PR=0.56; 95%CI: 0.34-0.91, but higher in Masaka compared to Mityana women, adj.PR=2.25; 95%CI: 1.44-3.52. However, no significant differences were observed by HIV status disclosure adj.PR=0.89; 95%CI: 0.56-1.42.

6.0 Discussion
6.1 Simple screening measures could identify and target such women while interventions to reduce negative outcomes (stigma and violence) should include efforts to scale up male involvement. Rephrase, not very clear

A quasi-experimental study in South Africa showed reduced violence against women in the male engagement arm

Insufficient information is provided here

This statement has been rephrased for clarity as indicated below.

Interventions that involve engaging potential perpetrators of the adverse events, such as male involvement campaigns may attenuate or avert occurrences of these undesirable outcomes (stigma and violence). Such interventions have been found to be effective in some studies. In
South Africa, a quasi-experimental study done to test an integrated intervention designed to reduce gender-based violence showed reduced violence against women in the male engagement arm. (see page 26 of the manuscript with track changes).

6.2 Another study in Rakai district in Uganda had fewer self-reports of intimate partner violence in the male involvement arm

Insufficient information is provided here

This statement has been expanded for clarity as indicated below.

Another study done in Uganda to assess the impact of an intervention involving provision of a combination of intimate partner violence (IPV) prevention campaigns and HIV services showed reduced self-reports of IPV among women in the male involvement arm. (see page 26 of the manuscript with track changes)

6.3 More than half of the women in this cohort were young women (<24 years) who face a number of other challenges of motherhood. Defined as less than how many years?

We have included the age in our revised statement.

More than half (52.2%) of the women in this cohort were young women (<24 years) who face a number of other challenges of motherhood. (see page 27)

7.0 Recommendations

7.1 Similar studies should be carried out to identify the perpetrator of the negative events since women disclosed to a wide range of people. Rephrase

This statement has been rephrased below:

Research that can explore and characterize the perpetrators of the adverse events, and the circumstances that lead to these events will be needed to inform the design of interventions that
can prevent the occurrences of these unwanted outcomes. (see page 28 of the manuscript with track changes)

8.0 Presentation of Tables

8.1 Table 1

Age category
15-24, 25-29, 30-34 Why represent ages in these categories? They are all of differing sizes which makes it difficult to compare.

Age categories was based on definition

15-24 ---- WHO definition for youths; youth have special needs and programs to address their challenges
25-29 ---- have the highest pregnancy rates and HIV-infection in Uganda
30-34 ---- Beyond 30, None were older than 34

Such age categorization guides programs that address health and social challenges when they know which ages to focus on. So the group size does not affect the analysis.

Lower secondary (ordinary level)

I’m not familiar with this term, is this standard for education level?

For clarity, the term ‘ordinary level’ has been deleted.

For education level, we have maintained two terms;
Lower (grade 1-4) secondary and Advanced (grade 5-6) secondary.

8.2 Table 2
Persons most commonly disclosed to. What about the proportion that disclosed to multiple individuals? See Table 2 with details added to reflect the proportions of women who disclosed to multiple individuals at visit 1 and 2.

8.3 Table 6
There are 14 health workers involved in PMTCT: 2 nursing officers, 8 midwives, 2 counselors and 2 expert clients

What is an expert client?

An expert client is a term used to refer to a client who has undertaken all the chronological steps/stages of the HIV continuum of care that people living with HIV go through from initial diagnosis to achieving the goal of viral suppression. The stages of the HIV continuum of care include (1) HIV testing/diagnosis, (2) linkage to HIV care, (3) engaged or retained in care, (4) prescribed and adhering to antiretroviral therapy, and (5) achieved viral suppression.

Many implementing partners in Uganda such as Mildmay Uganda and PREFA usually facilitate these expert clients to track fellow clients who are lost-to-follow up.

EID mother-baby pair reviews are done monthly post-delivery for the first 6 months and continued 3-monthly until the baby is 18 months. EID - define

This abbreviation (EID) has been added to the list of abbreviations on page 29 of the manuscript with track changes.

After delivery, women who are due for transfer from ANC are escorted by an expert client to the ART clinic and handed over to the provider on duty. Expert client? Same explanation as above - refer to the definition of an expert client indicated above.