Author's response to reviews

Title: "Just like fever": a qualitative study on the impact of antiretroviral provision on the normalisation of HIV in rural Tanzania and its implications for prevention.

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Author's response to reviews: see over
Dear Sir,

Thank you for reviewing our paper "Just like fever": a qualitative study on the impact of antiretroviral provision on the normalisation of HIV in rural Tanzania and its implications for prevention (MS: 1618934961270853).

The constructive feedback has helped us to strengthen the paper and clarify any potential ambiguities. We have carefully considered all the suggestions made by the reviewers and have uploaded a revised version of the manuscript together with an additional file containing the informed consent sheets used during the recruitment of study participants.

Our specific responses to each of the points raised are as follows:

**Reviewer 1 - John Yanessa**

1. I would be interested to know the mean age and gender of the participants (Included in Methods).
   Three tables have now been included in the methods section describing the profile of the study participants by age, sex, area of residence and other variables as appropriate (see tables 1, 2 and 3).

2. pp 3. Please change "HIV+ people" to the preferable "people living with HIV", and edit this throughout the manuscript. Occurs bottom of page 6 as well.
   The terminology used has been amended as suggested.

3. pp 4. Please change Sexual Transmitted Diseases to Sexually Transmitted Infections.
   Text amended accordingly.

4. pg 6. remove the use of "et al" in written text. It should more properly say "and colleagues")
   Text modified as suggested.

5. A complete review of the manuscript for run-on sentences (Page 17, second paragraph, last sentence. Sentence can be separated after reference 63), missing periods(Pg 17, after reference 62, and general flow).
   The paper has been edited by a co-author who is a native English speaker.

On page 7 the social-ecological setting of Kisesa is mentioned, perhaps for context only. It might be interesting to consider whether thematic responses might differ based on Religious background? Pages 12-13 allude to HIV/AIDS being a "moral disease", and "Witchcraft" seeming to be a socially accepted explanation. Although there is the usual and expected small sample size, possibly stratify by religious affiliation...this would be an interesting discussion point.

**We did not systematically collect information on church affiliation in this study. However, as the data suggested that religious beliefs may influence ART adherence, we designed another qualitative study which aimed to explore faith leaders’ perceptions of HIV treatment. The results of this study will be presented in a symposium on “alternative treatments” at the Aids Impact conference that will take place in Gaborone, Botswana in September 2009. (“Driving the devil away” - Holy water, prayers, and other miraculous cures for AIDS in a semi-rural Tanzanian ward. Assigned Session: 30.6: 14:00-16:00 24/09/2009).**

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

The paper has been edited by a co-author who is a native English speaker.
Reviewer 2 - Sabrina Bakeera-Kitaka

1. The data are sound; however a summary of the quantitative data needs to be included in the abstract, for example knowledge of the description of the population studied, age, and sex dispersion.

A table has been included in the methods section to describe the study population (persons who had registered at the ART clinic) as well as the profile of participants in individual interviews (by sex, age, area of residence, ART status and adherence to clinic appointments) (see Table 1). A second table describes the profile of participants who attended the group discussions (Table 2) and a third one describes the profile of the service providers participating in the study (Table 3).

2. Are limitations of the work clearly stated? No clear limitations stated.

At the top of page 19 we refer to “the small sample size that characterizes qualitative studies” as a limitation of this study. We also mention the fact that individuals accessing ART during the two first years of its availability might have been particularly motivated and thus not representative of patients attending the clinic in later years. Additional study limitations like the potential for “courtesy bias” were also acknowledged by the authors in the same paragraph.

3. Do the authors clearly acknowledge any work upon which they are building, both published and unpublished? The authors have published previous work: Roura M, Busza J, Wringe A, Mbata D, Urassa M, Zaba B: Barriers to sustaining antiretroviral treatment in Kisesa, Tanzania: a follow up study to understand attrition from the ART program. Aids Patient care and STDs 2008, 23(3).

As mentioned in page 5 (second paragraph), this study was part of a broader research project that aims to investigate uptake and impact of ART in a rural Tanzanian ward. Publications in peer-reviewed journals that are related to this broader study are referenced in the same paragraph.

4. Do the title and abstract accurately convey what has been found? The Title is misleading. However, with further reading it is clear what the authors are implying in their title. An interesting way to intrigue the reader.

This study describes perceptions of ART from the users and service providers’ perspectives. The overwhelming majority of respondents who were on ART reported feelings of “normalization” as reflected in the title. However, as we detail in the discussion section, despite many clients’ positive feelings and the empowering attitudes of service providers, there are reasons to believe that HIV is not (yet?) “normalised” within the wider community.

Reviewer 3: Daniel Tarantola

This article results from a nested study within a broader project aimed at the monitoring of ART provision in a rural community/area of Tanzania. The authors state that “this qualitative study investigated the impact of ART availability on HIV perceptions in a rural ward of North Tanzania and its implications for prevention.” The method applied to this qualitative study combined individual interviews (People on ART and care providers) and group discussions. While it is timely and important to investigate
roots, manifestations and impacts of stigma on sustained access to and use of ART, the work presented suffers from major flaws:

1. The interviews of 41 people on ART did not extend to people who may have been on ART but dropped out—perhaps precisely as a result of sustained or exacerbated stigma. The conclusions of the study apply only to the convenient sample of PHIV who were on ART at the time of the study, thereby providing a selective, incomplete and truncated information on the interplay between stigma, disclosure, adherence to treatment and preventive behaviours.

Not all the interviewees were on ART at the time this study was conducted. The study participants were selected from a sampling frame that included all Kisesa residents that had registered at the ART clinic. Clients with both regular and irregular clinic attendance patterns were purposively selected in order to obtain a diverse range of views and experiences (for more details see: Wringe A, Roura M, Mbata D, Busza J, Urassa M, Zaba B: Doubts, denial and divine intervention: Understanding delayed attendance and poor retention rates at a HIV treatment program in rural Tanzania. AIDS Care 2008, 21(5):632-7).

Half of the interviewees were on treatment and adhering to clinic appointments (21/42) reflecting the distribution of ART status and adherence in the sampling frame (33/66 on ART with good adherence). However, many interviewees had not yet initiated treatment (mostly because their CD4 counts had not declined low enough to meet the eligibility criteria) and a few had discontinued treatment for at least one month (4/66 in the sampling frame, all of whom were included in our study and accepted to be interviewed). To make this point clear we have added a table in the methods section that describes the characteristics of individuals included in the sampling frame compared with the characteristics of those who participated in the in-depth interviews (see Table 1). We have also changed the terminology used in the abstract from ¨ART clients¨ to ¨ART clinic clients¨ to better reflect the fact that individuals who had registered at the ART clinic were not necessarily on treatment at the time that we conducted the study.

The results presented in this paper relate mainly to the reports from ART users who consistently referred to the normalisation process described by the authors. However, the study design (in particular the interviews with individuals who had interrupted treatment and with service providers, as well as the group discussions) allowed us to identify possible causes of treatment interruption. Furthermore, the role played by stigma and denial was clearly acknowledged on page 14:

¨However, when stigma was experienced within the family, consequences could be harder to overcome and even result in treatment interruption¨ (page 14, second paragraph)

¨Family-level “denial” could heavily influence individuals’ health seeking behaviour, preventing HIV testing and even leading to attrition from the ARV program¨ (page 14, last paragraph)

2. While the study design suggests that it involved care providers, no specific information seems to have emerged from this source—at least there is no reference to it. The numerous quotes from PHIV interviewed are illustrative of selected points of view and experiences, but the article makes no reference to what might have come out from other components of the study (e.g. focus groups), or from dissenting voices.

There were several quotations in the text accounting for the service providers’ and group participants’ perspectives (pages 11, 12 and 15). It is worth noting
that feelings of "normalization" were identified mainly through individual interviews, as the group activities were centred on identifying the potential barriers to ART clinic attendance that would be faced by a hypothetical member of the community. The data gathered through the group discussions helped us to elaborate our discussion and conclude that a widespread de-stigmatisation of HIV hadn't (yet?) taken place.

The crucial role played by service providers in the process of "normalization" was described at the top of page 12.

An active seeking of "negative cases" or "dissenting voices" characterized the analysis process of this study as reflected in the second quotation on page 13 and the last paragraph of the same page.

For some, however, the fear of admitting their status persisted and reflected the very real negative consequences that could ensue: "I told him and he said: if you are in that condition then we will have to separate” (female, remote rural area) (page 13)

In spite of the reduction of internalised stigma and the trend towards a "normalisation" of HIV, participants sometimes referred to having been excluded, mocked, feared and blamed by members of their community” (Page 13)

Furthermore a "conflicting" quotation was deliberately used to conclude the results section. This aimed to anticipate several of our discussion points, which centred on considering our study findings in the light of other studies and the broader community context (see page 15, last paragraph). The identification of "dissenting voices" also informed the development of a subsequent study in which we investigated perceptions of ART from a broader community perspective, and which confirmed the existence of opposing forces operating between ART provision and HIV stigma. (Roura M, Urassa M, Busza J, Mbata D, Wringle A, Zaba B. Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania. Sex Transm Infect, 2008. Epub ahead of print)

3. The focus on stigma is clearly stated but passing references to discrimination are confusing. Stigmatization and discrimination are two linked, yet different processes (e.g.; the focus on stigma is largely examined from the perspective of the relationship between PHIV on ART and the community/family environment. Does stigma prevail in the health care setting and if so, does it result in discrimination?).

As described in page 12, neither stigmatizing attitudes nor discriminatory behaviours prevailed at the ART clinic or at the HIV testing centre. On the contrary, attitudes towards ART clients in this setting were often supportive and empowering. However, as we mention at the end of our discussion section, "courtesy bias" might have influenced some of the participants’ responses. Nevertheless, the supportive role of health professionals was confirmed by clients’ reports (see second quotation on page 12). We acknowledge that both stigma and discrimination might prevail in other health care settings.

4. The study is gender-blind.

The qualitative software NVIVO helped us to actively look for gender patterns. While we did not identify any gender-specific differences, we acknowledge that the study sample is too small to draw clear conclusions about this. The text has
been amended on page 19 to make this point clear: “The small study sample also limits our ability to identify patterns by sex and age”.

We hope our comments clarify these points, and we look forward to the acceptance of our paper.

Yours faithfully,

Maria Roura
(On behalf of the co-authors)