Author's response to reviews

Title: The people living with HIV stigma index: an exploratory study measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa

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Author's response to reviews: see over
The Editor
BMC Public Health

Dear Prof Latkin

Re: Dos Santos et al. An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the people living with HIV stigma index (MS ID: 1778069828978036)

Thank you for the reviewers’ comments on our manuscript: ‘An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the people living with HIV stigma index’ Please find attached the revised manuscript.

Please see below for a point by point response as to how the individual comments from the reviewers were addressed.

In general the following key changes were made:

1. The entire statistical analysis was redone and the results section rewritten. We hope that this provides a more meaningful representation of the data.
2. The discussion section has been extensively revised according to the revised results section.
3. Throughout the paper every effort has been made to remove duplication and redundant text in order to shorten the manuscript.
4. Spelling/typographical errors have been corrected.
5. We have also revised the title to be more reflective of the purpose of the study – as opposed to the previous emphasis on the study tool.

The new statistical analysis was done by Prof Piet Kruger; he has now been included as an author, while Alheit du Toit has been removed as an author (with his agreement) and his contribution acknowledged in the Acknowledgements section.

We trust that we have adequately addressed the concerns raised by the reviewers and that the paper is now significantly improved and suitable for publication in BMC Public Health.

We look forward to your response.

Monika dos Santos
Response to reviewer comments

Reviewer 1

Referencing: The authors need to generally improve their referencing of the article. Take an example of the first paragraph, a number of ideas appear, yet there are two references for a whole section. The authors report that history provides an unfortunate abundance ….but this statement is not referenced. The second paragraph is long with the single reference number 1 covering a number of issues. Clearly, the study referenced as number 1 couldn’t have looked at all these aspects of stigma. Throughout the introduction, whole paragraphs with multiple ideas have single references. See pages 2,3,4. A concerted effort has been made to reference extensively with appropriate and representative sources.

The authors repeatedly use inappropriate referencing styles while quoting studies. Take an example of Holzemer, Human, Arudo, Rosa, Hamilton et al 2009. Usually the case would have been ‘in a study by Holzemer et al.(2009). When referencing more than two authors, we have now amended all the relevant citations to the first author – and then et al (we could find no specific directives in the instruction for authors concerning this).

The use of words like ‘an international sample of 726 participants’ is equally inappropriate. We have reformulated the sentence to exclude the term ‘international’.

Instead of naming all countries in which a research was conducted, the authors could simply state that in a multisite study, and then reference the information. This is repeated a number of times in the text. We have rephrased this sentence, it now reads ‘… to build an evidence base to make it possible to compare data across countries’

Specific comments

The authors state that a target sample size of 500 was determined by available resources and time constrains. How can the authors convince readers that their study was adequately powered if they never conducted any power calculations a priori? The authors go ahead to state that it was believed that 500 were ‘adequate’. Against which assumptions does the author base their arguments? Due to resource limitations, the study was intended to be an exploratory study rather than a definitive study with a representative sample per se (and hence it is not powered) - we have now made the term ‘exploratory’ more explicit - and hope that this suffices.

Why did the authors choose to conduct a convenience sampling? How can the reader be convinced that such maneuvers didn’t lead to selection bias since it can be inferred that the research assistants would only choose those they felt like interviewing? We had to make use of a convenience sample due to resource constraints – however, having said this, FPD supported ARV clinics are situated at the epicenter of the HIV epidemic – so in all likelihood we would not have been able to find better sites even if we had had the financial resources. We have now mentioned, however, the potential bias in the limitations section when we state that only participants from FPD supported sites were recruited. Whether a convenience sample or not, in our view there is always a risk of fieldworker selection bias, we did emphasise in their training, however, that anyone who can provide informed consent and fulfills the eligibility criteria (HIV positive, over the age of 18 etc) may participate. We also trained FPD area managers.
(responsible for the different ARV clinics) in the study – and they, together with the investigators, monitored the fieldwork activities. There is also an ethical issue to consider which we think is important. HIV/AIDS is not a notifiable disease; and even if it were, one cannot access confidential medical files to identify potential participants. At the clinics the participants had already voluntarily disclosed their status. This is another reason for using counsellors to whom they were known: to request participation.

The authors state that patients with mental health disabilities were excluded/avoided. How did they arrive to such conclusions? Was this done by mere looking at patients? Which mental health disabilities are the authors talking about?

The section has been rephrased to clarify this: ‘Every effort was made to avoid interviewing those with medically documented severe mental health disabilities (such as dementia or psychosis) that could have impaired their ability to provide informed consent.’

For a first time reader, the PLHIV index needs a bit more description. For example, could the authors explicitly state what it measures? Of critical importance is a reference to this scale. How used it first? Has it been validated in any setting? The authors seem to state that this scale can be altered/was altered and some items added with regards to the South African context; this makes the reliability of the scale questionable. More explanation will be needed to clarify this. We have now referenced the index and provided more explicit information about what it measures/ the domains it covers. To the investigators’ knowledge this is the first time that the index has been brought to the publishing arena, and that it has not been formally validated before. However, there are study reports available online from various countries – this has now been stated explicitly in the report. We only altered the section mentioned in the article so that those questions were no longer open-ended – we needed to quantify all data due to the scale of the study and the resources – we have now stated so in the article.

In the data analysis section, it would help if the authors state which variable was the outcome variable and the predictor variables. We have now included this aspect and hope this suffices. We tried to clarify this where the analyses are described. Mainly, measurements of stigma and discrimination were combined to provide a measurement of this, and in the same was done for internal stigma. These would be the ‘outcomes’ and the extent to which these could be predicted by the various biographical variables (as independent variables or predictors) were explored.

The Authors give 8 pages of results!!!! Certainly this is very long and exceeds the word limits of most results sections. The result section needs to be made tighter, reporting only significant results, and avoiding the use of words and explanations all through this section. We realise it is quite lengthy, but the index itself is quite long due to all the domains it covers. In actual fact, we initially left out three of the sections (internalised stigma, having children and main problems and challenges experienced) due to the fact that we had so much data. We have tried to keep the results sections as concise as possible by only reporting on the most pertinent aspects, although we have now included the domains initially left out due to the 2nd reviewers’ feedback. However, every effort has been made to shorten this section by removing duplication between tables and text.

In the discussion, the authors abandon the abbreviation of PLHIV and state it in full. In page 20, section paragraph, the authors make a 5 line single paragraph sentence, these need to be
corrected. Both these aspects have been amended.

Table 2 needs to be formatted so that it looks neat (the variable rows). Table 2 has been formatted so that is now standard (although the tables have now been shifted around due to the reformatting of the results and discussion section – in accordance with the feedback received from the second reviewer).

Reviewer 2

ABSTRACT

(I make some suggestions here but accept that the style will be framed by the journal requirements)

Background: The first sentence in the background reads like a concluding sentence. The background should introduce the topic and provide some indication of what you aim to do in the study. This has been amended.

Method: You need to state what the stigma tool is and what it is designed to measure, particularly since the instrument has not been widely used, as you point out in your introduction. The convention is also to state the study design e.g. cross sectional, survey etc. All these aspects have now been attended to, and the term ‘survey’ has been included in the title. We have also rephrased the title of the paper.

Results: should be more than a general statement and can include the most significant findings, including some statistics. We have reformulated the results to be reflective of the more significant findings.

Conclusion: While your results suggest that the rights of marginalised groups are impinged there are other findings that might be highlighted here. Currently your conclusion seems to select one aspect of your study rather than be a reflection of the study as a whole. We have reformulated the conclusion to be more reflective of the entire study.

INTRODUCTION

General comments: be aware of selecting emotive, value laden language (e.g. ‘an unfortunate abundance’, ‘sadly’). In scientific writing you are presenting evidence highlighting the relevance and importance of your subject. You are showing the audience the evidence rather than giving your opinion which is the impression that I am getting as it stands now. Your pen is your sword here! We have omitted the overly emotive language.

Your statements must be referenced even if historical in nature. Referencing has been updated here and throughout the manuscript.

It is very important that you paraphrase the literature of others that you cite rather than use the same words otherwise you can be accused of plagiarism. If you ‘close’ a sentence you need to provide the reference, for example, Paragraph 2, Line 8. We have rephrased this section and referenced it more extensively.
I would suggest using (Goffman 1963) rather than the Oxford Dictionary as a reference for your first sentence. Goffman has replaced Oxford Dictionary as a reference.

At the beginning of the third paragraph you say that HIV/AIDS related stigmatisation is associated with many factors and you give examples and should reference these. Try and use the same terminology throughout the manuscript i.e. HIV-related or HIV/AIDS related stigma. These have now been referenced – and the HIV/AIDS term is now used consistently.

The Household Survey that you refer to – was the same survey administered in 2002 and 2005 as is suggested? Yes, it is administered every couple of years. And why have you referenced the ‘National Strategic Plan’ here as well, is it relevant? Agreed, we have now removed the NSP reference as its not really relevant.

How is religion and consultation with sangomas wrapped up with stigma? Some might argue that religion preaches tolerance and charity. Your must explain and cite the evidence. We have removed this section as the index did not measure any links between stigma and sangomas/traditional healers.

The sixth paragraph needs polishing and the literature cited paraphrased. Are you saying low status feeds stigma? Reference 14 is not peer reviewed and while it can be included there are other references that could be better cited. This paragraph has been rephrased – and yes, the implication is that woman still have a low status in many traditional (rural areas in particular) African cultures – and thus carry much of the ‘blame’ for the spread of HIV. We have changed the reference to a more suitable source.

The first sentence of the seventh paragraph could be worked into a concluding sentence for paragraph six leaving paragraph seven to summarise and then state the aim of this work. Given the relative novelty of the instrument I would be inclined to introduce and discuss its application in the introduction rather than the methods since this section should be describing, succinctly, what you did and how you propose to analyse your data. It would also be useful to define the various types of stigma since the index clearly categorises the items accordingly. This is also important because you claim that the index is a tool to ‘empower the individuals and communities most affected by the epidemic’. This section of the introduction has been rewritten. We have also moved the description of the index to the introduction section – and we have discussed the different domains/contexts in which stigma is studied.

I think that while the questionnaire is comprehensive in terms of its capacity to measure personal, structural and political constructions of stigma, it is really the design of the study that will result in an empowerment of individuals and communities (i.e. what else is going on in the study) rather than the questionnaire itself. Although I acknowledge it is well known that subjects in research studies may modify behaviours as a result of being ‘studied’ (Hawthorne Effect). In the light of this you may want to consider how much prominence you give to this idea that your study is empowering unless your results can demonstrate this in some way. You could of course discuss this aspect and perhaps comment on this when you state your rationale for choosing this index over another stigma questionnaire. We have modified the text to state that the ‘empowerment’ aspect of the index was the reason why we chose to use it, however, we have also now explicitly stated than any potential empowerment was not directly studied or measured within the context of the study (ie, it fell out of the direct and tangible scope of the
study).

METHODS

The detail about how the study was conducted is fluent and interesting and demonstrates the scale of involvement of the community members and the complexity of the project. The importance of this could be discussed later and referenced against other operations research. We have made it explicit that although the study design aims to empower PLHIV communities, this aspect was not measured in the study, we have also made study outcomes comparisons to other PLHIV Sigma Index reports (eg Kenya, Nigeria etc).

Study population and design: while you may not have planned your sample size you may be able to say something about it retrospectively, as it reads currently it is not very scientific! You might refer to eligibility criteria. There is a lot of detail about ethics which is probably unnecessary particularly in relation to how you achieved anonymity with coding. However, I appreciate that it is important to demonstrate how you protected your participants and it provides a model for others conducting research in the community. But it is probably unnecessary to reference this section with a text on the conduct of social research. With regards to sample size, we emphasised that this was an exploratory study. We have removed the reference on the conducting of social research.

The PLWHIV Stigma Index: I would have liked to see this discussed in the background particularly since it seems that this is the first time that data collected using the questionnaire has been brought to the publishing stage. The index should be referenced since currently it is not. We have moved this section to the Introduction – and have discussed the background of it in more depth, and we have now referenced it.

I think your reference to data triangulation in the seventh paragraph of the Methods may not be correct where it is situated but fits with using different methods to collect data thus contributing perspective, as you point out later in the paragraph. We have removed the reference to ‘data triangulation’ in the 7th paragraph.

Other data collection tools should be described here as well. It might be useful to point out what information was not available. Currently your methods only describe the ‘index’. We have made it explicit now that only the direct index responses were recorded, analysed and reported on.

Data analysis: Reference SPSS Version and company, it is a convention. You might discuss the level of significance that you employed and how you propose to report your statistics. Again reference to reference 15 is probably not required. The comment about CHAID is not relevant unless this is how you employed it in your own study e.g. we used ....for - STATISTICA has now been referenced, we have removed the CHIAD reference.

RESULTS

Demographic data: Comment about the differing proportion of patients at each centre (later you will need to account for how you managed to overcome this statistically unclear here what the reviewer means). But I would leave out the comment about ‘resistance from management’ in this sentence. We have cut this out as it was an isolated situation. If you think it is relevant rephrase and add it to the limitations of your study. You only need to reference Table 1 once at
the beginning e.g. ‘the demographic characteristics of the 486 patients can be found in Table 1’. Amended. Were some men not identifying as ‘gay’ but classifying themselves as ‘men to men’ sex? We don’t know, we can only report on the data that we obtained, we have though stated now that this is a possibility. You will need to be careful with this terminology because of the international readership. The editors may be able to advise what is culturally appropriate here. We have used the term ‘men who have sex with men’ for now as this is the term adopted for key populations by UNAIDS etc. currently. Try not to repeat what is in the table and include data that was not tabulated e.g. as you have done with the food and the villages. An effort has been made throughout to avoid duplication between tables and text. Could you reference the information on small towns/cities etc against the regions listed in the tables? That would be interesting in term of your findings, described a bit later, and inform international readers. Its very difficult to as all the provinces listed in the table have regions that are both rural and urban – Gauteng is more urban – but it has a number of rural areas as well, and the other provinces are more rural – although they also have urban centres. Note however that we had to limit the interaction between province and area to Limpopo and Gauteng for this type of reason: e.g. there were no ‘urban’ participants from Mpumalanga; and few ‘small town/village’ participants from North West. For an explanation of population demographics in the provinces we have referred readers to Statistics SA web page, so as not to add length to the article.

Paragraph Five: I suggest removing the word ‘themselves’ it implies that others might disclose on their behalf (and is a tautology) - but your assertion in the last sentence belies this. ‘Themselves’ has been removed.

General comments: You have, in general, divided your results into sections referencing the format of the ‘index’ which is logical (and makes it easier to review) however internal stigma is lumped under ‘experience of stigma and discrimination’. Current literature on the topic of stigma highlights the importance of disentangling the construct, and since the ‘stigma index’ does (disentangle) stigma I would suggest that you continue to divide your results according to the ‘index headings’. We did not initially reported on our internal stigma and reproduction data due to length of the article, but have now included these domains. Experiences of stigma and discrimination fall under another subsection of the questionnaire and have thus been included in the relevant section. We have also reorganized the divisions according to that of the index.

I would add a section for pregnancy and reproduction and reconsider the heading and the data under ‘effecting change’ which I think should be ‘affecting’ change. ‘Effecting change’ is the heading used in the original index, and the aspects of pregnancy and reproduction fall under the section of ‘Having Children’ which we have now included in the results and discussion section (as well as Internal Stigma and Main Problems & Challenges Experienced). The paragraph above the heading for example seems to fit better with this heading. You might also highlight differences between regions. Doing this will help you structure your discussion better. The results section has been rewritten completely following consultation with a statistician as advised.

Your tabulated data could contain results of your statistical analysis. Currently you just cite percentages in all of them. The reporting of discriminant analyses is incomplete, and the results could be tabulated. It is not clear what all the bracketed values throughout the results mean. If R values then this should be in the brackets. In addition the value of 1.034 pertaining to ART takes a value of greater than 1 so cannot be a correlation coefficient as are currently presented. I
would recommend consulting a statistician. We have consulted with a new statistician who redid all the statistical analysis from the raw data – consequently the entire results section of the article has been revised and results presented according to the new analysis.

**DISCUSSION**

While fluently written the discussion might be easier to follow with headings given that there are so many results to address and it is easy to get lost in them. The first part of the discussion should be a statement of the major findings but the first paragraph does not achieve this. Next one would expect reference to other studies relevant for the findings in this study which again could be categorised according to the ‘index’. Of interest might be a comparison of the findings from different regions while reminding the reader of the geographic/demographic context. We have reorganized the Discussion section under several headings, and have rewritten large parts of this section to reflect the major findings and improve the flow of the section. The headings do not strictly follow the subsections of the index, as some sections have been combined to avoid duplication.

There are some aspects of the study that are tantalisingly unexplored. One example is the finding that despite their high educational level, teachers were ‘enacters’ of stigma. The assumption made here is that the teachers need more education about HIV/AIDS. Might this finding say something about the nature of stigma? That it transcends educational background? In addition to this the notion of internalised stigma and how people limit their own lives for fear or anticipation of stigma could be better explored. We have taken out the suggestion of more education needed, and replaced it with further research as we don’t want to second guess as to why this is the case.

With regard to the observation that people living in the poorest households were less likely to be on ART than people in affluent households, was there equal access to treatment? Were they more likely to live in rural or urban areas? What are you implying? That stigma stops people taking treatment? Does your study support that assertion? This section has been completely removed as a very large proportion of subjects were taking ARVs/or had access to it (as would be expected from a population drawn from an HIV/AIDS clinic population). In light of this, any conclusions drawn from this would be misleading.

With regard to access to ART and IDU, how are the findings similar to the Dos Santos 2010 study? In the demographic section you say there that 1.2% of the sample are injecting drug users and then in Table 2 a reference is made to n= 87/486 as injecting drug ‘partners’. This section has been removed, see above.

You make mention in paragraph 5 of a ‘positive outcome’ of the study being that the ‘majority of participants indicated that they had had constructive discussions...’ Is this an outcome of your study? Or is this an encouraging finding of your study? We have changed the wording to ‘encouraging finding’

While I recognise the importance of citing local studies and a number of important and relevant studies/reviews are indeed cited here, including Parker and Aggleton’s work on structural examples of stigma, I would suggest exploring the wider literature on the topic and offer some suggestions. Thank you for the reference suggestions, we have now incorporated a number of them.
Typographical errors: There are a number of typos – mainly in the reference list. We have attended to the typographical errors both in the article and reference list.

Here are some suggested references: The suggested articles below that have been highlighted in yellow have now been incorporated into the article.


Izugbara, C. O. and E. Wekesa (2011). "Beliefs and practices about antiretroviral medication: a


