Reviewer’s report

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

Version: 3 Date: 25 July 2013

Reviewer: Susan Herrmann

Reviewer’s report:

General comments:

The authors present the findings of an important study conducted in the epicentre of the HIV/AIDS epidemic. While access to lifesaving and tolerable treatment is becoming more widespread in the regions affected, social stigma continues to influence prevention and testing for the infection. In addition stigma can cause emotional distress for people with HIV and their families, and result in reduced quality of life and constrained life choices. Difficulty understanding stigma as a social construct and cultural and contextual nuances also complicate public health measures to address problems arising from this social consequence of HIV infection. Therefore, current research in this subject is critically important at an individual and policy level.

This is a fluently written manuscript reporting findings of a large study in four provinces in South Africa. The findings are relevant to people living with HIV and policy makers planning HIV/AIDS care. As it stands however, it falls short of its potential. In particular it fails to deconstruct the complex nature of stigma which is necessary in order to tackle the problems arising from it. The manuscript will benefit from revision on a number of levels and I suggest that the authors undertake this before a final decision on publication can be reached.

Specific comments related to the various sections follow.

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.

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.

Results: should be more than a general statement and can include the most significant findings, including some statistics.
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.

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!

Your statements must be referenced even if historical in nature.

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.

I would suggest using (Goffman 1963) rather than the Oxford Dictionary as a reference for your first sentence.

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.

The Household Survey that you refer to – was the same survey administered in 2002 and 2005 as is suggested? And why have you referenced the ‘National Strategic Plan’ here as well, is it 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.

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.

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’.

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.

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.

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.

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.

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.

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’.

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 .....
‘men to men’ sex? 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. 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. 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.

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.

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’.

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.
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.

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.

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.

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.
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?

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'.

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?

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.

Typographical errors:
There are a number of typos – mainly in the reference list.

Here are some suggested references:


