Author's response to reviews

Title: Internalized stigma among patients with schizophrenia in Ethiopia: a cross-sectional facility-based study

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Version: 3 Date: 15 December 2012

Author's response to reviews: see over
**Authors’ responses**

Dear Dr Olino,

We are submitting our responses to the reviewers’ comments. The details are given under each comment. We are grateful to all the reviewers for their kind review and constructive comments that we believe has improved the quality of the paper.

Yours sincerely,
Dr Abebaw Fekadu
On behalf of the authors

**Reviewer’s report**

**Title:** Internalized stigma among patients with schizophrenia in Ethiopia: a cross-sectional facility-based study

**Version:** 2 Date: 17 October 2012

**Reviewer:** Philip T Yanos

The authors addressed many of the comments. There are some minor modifications, indicated below, that would further improve the manuscript.

**Major Compulsory Revisions:**
- None

**Minor Essential Revisions:**

Background: The authors added a definition and more thorough explanation of research on self-stigma/internalized stigma. But their initial definition of “internalized stigma” is not wholly consistent with the typical definition in the literature (page 4)

*Response: We have modified the sentence by deleting the phrase “assumes that other people would devalue or reject them” and expanding on the definition.*

The question the authors used to evaluate whether or not stigma contributed to discontinuation of meds is very leading. This method is fine, since that’s a difficult question to assess for a variety of reasons, but it’s important to discuss this as a weakness more clearly in the limitations section.

*Response: We have acknowledged this by adding explicit statement on the potential limitation of having a leading question.*

• Results: authors say that “stigma was the most important factor for their decision to discontinue their medication”—but in the methods there’s no evidence that they asked about other factors. So either methods need to be clarified, or this
sentence needs to be rephrased.

Response: It is true that we have not measured additional factors. It is only in relation to the additional clinical and demographic factors that were measured and entered into the model. We have modified the sentence to avoid ambiguity.

Discretionary Revisions:

Background: the authors indicate that exploring stigma across cultures is important, but didn’t really touch on any theory for why. May be that there’s not enough space for this?

Response: We have provided additional details now but as we have not actually explored the role of culture in this study, we feel that further detail on the subject would be beyond the scope of the study.

Results: The sentences on impact of education on stigma phrased in a contradictory way (p.15)

Response: We have rephrased the sentence and we have the message is now clearer and consistent.

Level of interest: An article whose findings are important to those with closely related research interests

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

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests.

Reviewer’s report

Title: Internalized stigma among patients with schizophrenia in Ethiopia: a cross-sectional facility-based study

Version: 2 Date: 21 October 2012

Reviewer: Jamie Ringer

Reviewer’s report:

The authors of the article, "Internalized stigma among patients with schizophrenia in Ethiopia: a cross-sectional facility-based study," have made improvements to the manuscript in this second revision. The introduction is much improved. Still, some questions remain regarding
the methods of the study which require better explanation prior to publication.

Major revisions

It's difficult to ascertain the actual steps of the study. For example, the authors report administering the ISMI, but it’s not clear whether was it given to the participants after being translated, read to the patients, or “observer rated” which was stated in the response letter but not in the manuscript itself. “A: THE ISMI WAS OBSERVER-RATED (COMPLETED BY SENIOR

PSYCHIATRIC RESIDENTS). WE HOPE THIS IS NOW MORE EXPLICIT.” The term “observer rated” is interpreted as being completed by the rater without the patient’s input, but with the population being 90% literate and the nature of the questionnaire, being rated in this way would not seem appropriate.

Response: The instruments were read to the participants directly. For further clarity, we have offered a longer explanation under a separate heading (“administration of instruments”) at the end of page 9.

Under the section: Prevalence of Internalized Stigma, the authors report that patients experienced stigma within the family, neighborhood, and occasional disrespect from mental health staff. Where did this information come from? Specific sources of stigma are not measured on the ISMI, so was an interview additionally done? If so, this should be described in the methods section.

Response: Yes, we had asked additional questions to establish where participants experienced stigma. We have included this in the methods (page 9)

In the same section, please clarify the first sentence: “participants admitted experiencing at least one form of stigma at the time of interview”…what “forms” are being referred to?

Response: This is referring to endorsing at least one stigma item affirmatively. We have made this more explicit (page 12).

In the discussion section, the authors state that a high burden of internalized stigma is demonstrated and support this by the statement that three quarter of patients endorsed strongly at least one stigma item…can it really be said that the burden is high based on people strongly agreeing on 1 of 24 questions? This statement should be backed by stronger statistical evidence.

Response: We respectfully beg to differ. If over 90% of the participants endorsed at least one stigma item, with a three-fourths strongly endorsing at least one item, and nearly half of the participants scoring at a moderate or severe stigma levels, we feel comfortable to say there is a strong stigma burden.

In addition, at what point was informed consent sought? Prior to the chart review for eligibility or prior to administration of the ISMI, etc?

Response: Informed consent was obtained before a full chart review but after establishing that a particular person had a diagnosis of schizophrenia.

The authors have still not fully explained their exclusion of persons with “impaired insight.” How was insight level determined? And since lack of insight is a common problem in persons with schizophrenia, why were these individuals excluded? The authors explain that they feared these patients may lack capacity to give consent, but insight into illness and capacity to make decisions are separate issues. This exclusion should have also been mentioned in the participants section of the methods with the other inclusion/exclusion criteria.
Response: This is now included in the exclusion criteria. We agree that lack of insight is a crude measure of capacity. We are also likely to have excluded many potential participants. But lack of insight was simply taken as a proxy for capacity to consent. Assessing capacity would otherwise have been a complex process and beyond the scope of the study project.

Discretionary Revisions
Under the methodology section, there is a heading for participants, yet the majority of the data on participants is found later under the heading "socio-demographic and clinical characteristics." It would be helpful for the authors to combine these sections and seems more appropriately found in the methods section than in the results.

Response: The details on participants under the methodology relate to participants we intended to include prior to the conduct of the study. This was what was contained in the methods of the study prior to the conduct of the study. The details on participants under the results section is what we found in the study (i.e., was part of our finding). In a cohort study, a cohort of participants already exists prior to the conduct of the study. Therefore, description of the participants constitutes part of the methodology. In the case of a cross-sectional study, which is the case in our study, the participants are only known during the conduct of the study and would constitute part of the findings of the study.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.

Declaration of competing interests: I declare that I have no competing interests.

Reviewer's report
Title: Internalized stigma among patients with schizophrenia in Ethiopia: a cross-sectional facility-based study
Version: 2 Date: 12 October 2012
Reviewer: ilanit Hasson-Ohayon

Reviewer's report:
Dear Prof Lysaker,
Thank you for sending me the revised version of the paper entitled “Internalised stigma among patients with schizophrenia in a low income country: a cross-sectional facility-based study” to review. In this paper, the authors responded to the reviewers
comments. While most of the responses were appropriate and satisfactory, new information was added regarding the administration of the ISMI which raised a major concern. My main concern is that while the authors responded to the reviewers' comments they wrote that they used the ISMI as observer rate by the psychiatrist. They state it in the cover letter but not in the manuscript. I am not familiar with this version of the scale and cannot find data on such a scale. I cannot understand the reason for not using it as a self report. This is a popular valid self report scale – and any reason to use it as observer rate should be justified. Unless this version was proven valid – the study results are also questionable for their validness.

Response: We have briefly attempted to explain why the ISMI had to be interviewer-administered. On the other hand, it is sometimes necessary to use interviewers to administer questionnaires that were developed for self-administration. For example, the Self-Reporting Questionnaire (SRQ) is a widely used self-report questionnaire, which has been used as interviewer-administered tool. We had experience with using such tools. We do not feel this is a major limitation.

1-ISMI reliabilities were requested by 2 reviewers and the authors replied by providing kappa. Why kappa? Alpha cronbach for reliability – internal consistency is more appropriate for self-report continuing variables. Kappa is for nominal data-inter-rater agreement. The authors actually write in their response to one reviewer that the ISMI was observer rate by a psychiatrist. I am not familiar with this version of the scale. Usually, this is a popular self report scale – and any reason to use it as observer rate should be justified. Unless this version was proven valid – the study results are also questionable for their validness. This is a main issue that should be addressed. How can the psychiatrist report the self-stigma of their patients? Why not administrate it to the patients?

Response: The interviewers read the questions directly to the participants and rated the response of the interviewers. We have now reported on the Cronbach’s alpha (page 10).

2-It is not clear why the authors thought that low insight into the illness is related to the possibility of providing informed consent. It would be helpful if they can provide a rationale or references to justify this.

Response: We have used lack of insight as a proxy measure of the capacity of participants to provide consent. Although this use is logical, we agree that it is crude and we should have used another method to establish capacity. Additionally excluding participants without insight limits the generalisability of the report. But establishing capacity can otherwise be a complex process and we were not in a position to undertake this complex process.

3- reviewers comments that self-stigma and public stigma are not well differentiate. There are still some places that instead of stigma it should be written internalized or self-stigma and not just stigma.

Response: We acknowledge that it is important to be consistent in the use of terminologies. We have changed the words wherever we thought it would be appropriate to do so. Where we felt the use of the term “internalized stigma” is simply
repetitive and cumbersome, or where we thought the reference to internalized stigma would be implicitly understood, we have opted to use the term “stigma”. It should also be clear that there are places where we are simply referring to stigma in general.

4-It is not clear why the authors think that the comparison to European countries is valid-as they responded. It might be beneficial if they can explain why they think so.

Response: The reason for the comparison is twofold. First there is limited data on internalized stigma from Africa or other low income settings. Secondly, based on the findings of the WHO studies, stigma is considered a factor in the presumption of more favourable outcome in low income settings.

5-Additional comments regarding the presentation of results and discussion cannot be inferred until the first major comment will be clarified.

Level of interest: An article of importance in its field
Quality of written English: Needs some language corrections before being published
Statistical review: No, the manuscript does not need to be seen by a statistician.
Declaration of competing interests:
I declare that I have no competing interests

Reviewer's report
Title: Internalized stigma among patients with schizophrenia in Ethiopia: a cross-sectional facility-based study
Version: 2 Date: 22 October 2012
Reviewer: Megan Grant

Reviewer's report:
The authors have integrated the suggested changes into a thoughtfully presented summary of their findings with respect to internalized stigma within a population of individuals diagnosed with schizophrenia. The following comments are offered in the interest of improving this manuscript further.

Minor Essential Revisions

1."Background” section, third paragraph, “The finding suggests that personal experience of stigma may also be high [20].” In this section, it is somewhat unclear whether the authors are referring to internalized stigma when they say “personal experience,” or to some other aspect of stigma mentioned elsewhere in the background section (e.g., discrimination).

Response: Thank you. We have modified this to say “internalized stigma”

2.In the “Participants” section the authors refer to exclusion criteria as a “significant” level of cognitive impairment or substance abuse. While they have added in this revision of the manuscript that these judgments were made by senior psychiatry residents, there is still no indication of the criteria that were used to make these judgments. More information could be provided on how cognitive
impairment and the level of substance abuse were assessed.

**Response:** These were clinically established impairments and is indicated (page 8).

3. The point the authors make in the “Limitations” section about some outcomes being assessed using single questions could be expanded upon. Such expansion could focus on acknowledging the fact that these questions did not seem to be open ended, particularly the one aimed at addressing whether a participant’s experience of stigma contributed to discontinuing medication.

**Response:** We have now included explicit statement about the potentially leading and close-ended nature of some of the questions.

4. The first sentence in the “Conclusions” states that the results of the study “confirm” the significant burden of stigma in this population. This statement may be too bold given that this is the first study of its kind done in Ethiopia and given the limitations noted by the authors. It may be more appropriate in this section to continue with language similar to that used elsewhere in the manuscript when discussing findings, such as “suggests” or “supports.”

**Response:** Modified as per the recommendation.

Discretionary Revisions

1. In the “Background” section, second paragraph, in the sentences beginning with “Several studies have emphasized…,” and “Clinically, higher depressive symptoms…,” it could be made clearer whether the authors are referring to internalized stigma or public stigma. The same is true for sections in which the authors simply refer to “stigma,” (e.g., in the section, “Factors associated with stigma”), in which it may be more appropriate to refer to the “internalized stigma” measured in this study, in contrast to the public stigma measured in some of the research mentioned.

**Response:** We have made changes throughout the manuscript as per the recommendation above.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**
I declare that I have no competing interests.