Author's response to reviews

Title: Low trust of ethnic minority patients in in-hospital care: a qualitative study

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Author's response to reviews: see over
Reply to the reviewers
First of all we thank the reviewers for their detailed and relevant comments. We made use of these comments to the best of our ability and we believe that these adaptations added considerably to the clarity and readability of the paper.

Three replies to the reviewers (our reply to the comments is in italics):

Reviewer: Alexander Bischoff

Comment 1
“Low trust of ethnic minority patients after in-hospital care: a qualitative study” is a timely study addressing trust of ethnic minority patients in health care providers. It is a original research article contributing to the emerging literature on trust in patient-provider communication.

Comments to the points listed by the editors
1. Is the question posed by the authors well defined?
The authors sought to identify what conditions in hospital care cause feelings of low trust among ethnic minority patients. Trust is seen as a reflection of…; about trust, p 3 (comment to whom it may concern: the manuscript has no pagination; it is therefore cumbersome to refer exactly to specific points): A clear definition should be provided, not just “roughly defined”. Also in the literature review (background section), a number of studies related to trust should be quoted (cf. below), and the sentence “there are now no qualitative interview data available…” (p 4) should be deleted, or changed into “little data…”.

Reply 1
In the introduction we provided a more elaborated definition of trust now, based on the available literature (page 3-4). We also quoted and discussed some of the studies suggested by the reviewer (second paragraph of introduction on page 3 and last paragraph of introduction, page 5). We deleted the sentence “there are no qualitative interview data available…” and instead gave a more elaborate description of the lacunas in research (i.e, a few studies on the subject of low trust as well as a few studies on personal experiences with low trust rather than theoretical constructs of trust (end of p. 4, beginning of p. 5).

Comment 2
2. Are the methods appropriate and well described?
They conducted a qualitative study using semi-structured interviews with ethnic minority patients. While the methodological approach is perfectly suitable to the study question, more details about the interviews are needed in the methods section (not only in the results). It is not sufficiently clear where the data are taken from and who said what (group discussion? Individual interview? Type of healthcare they are referring to?)

Reply 2
We provided additional information about the interviews in the method section (p. 6-9). We clarified how we obtained the data into great detail, by answering questions such as where the data were taken from and who said what (section Data collection, p. 8-9 and an extra box (Box 1 on page 27). We also have added after the quotations of fragments of the interviews, the reference to the specific respondent, so that he/she can be found in this box.

Comment 3
3. Are the data sound?
As far as I can evaluate this, yes.

4. Does the manuscript adhere to the relevant standards for reporting and data deposition?
Yes.

5. Are the discussion and conclusions well balanced and adequately supported by the data?
While the discussion and conclusions are well balanced and adequately supported by the data, they should be contextualised with recent research findings on trust, for example

Another reason to reference papers like the above is the finding that the first pattern of low trust is related to language barriers, a point that could be more stressed and developed in the discussion.

Reply 3
Firstly, we included and discussed the above mentioned research findings in the introduction (second paragraph of introduction on page 3 and last paragraph of introduction, page 5)) and discussion (Discussion; last paragraph on page 18) sections of the revised manuscript.
Secondly, thank you, this is a very interesting point! We discuss the influence of language on low trust into more detail now in the discussion section (see Discussion, last paragraph on page 18).

Comment 4
6. Are limitations of the work clearly stated?
Only to some extent. A formal short study limitations section in the discussion would be helpful.

Reply 4
We examined the different study limitations into more detail (as well as some more strengths), see Discussion, section ‘Strengths and limitations), p 19-20).

Comment 5
7. Do the authors clearly acknowledge any work upon which they are building, both published and unpublished?
Yes.
8. Do the title and abstract accurately convey what has been found?
Yes.
9. Is the writing acceptable?
Yes.
- Discretionary Revisions (which are recommendations for improvement but which the author can choose to ignore)
- Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct)
- Major Compulsory Revisions (which the author must respond to before a decision on publication can be reached)
As Minor Essential Revisions
I would like to suggest the following:
Ad p 3 ‘Quantitative research is needed to explore the impact of the three patterns on patient’s feelings of trust’: a sentence normally not used in the conclusion of an abstract
Reply 5
We deleted the sentence ‘Quantitative research is needed to explore the impact of the three patterns on patient’s feelings of trust’

Comment 6
Ad p 3 ‘Roughly defined’ – provide exact definition (or develop that there is no exact definition)
Reply 6
We provided a more exact and elaborated definition of trust (first part of the introduction, page 3-4).

Comment 7
Ad p 5 ‘patients were included…’ More details would be helpful: Included how? Bias? From what immigrant organisations? How many different organisations? And: were interpreters used? (Yes, they were, but it should be detailed in the methods section).
Reply 7
In the method section we gave more information about how respondents were included, from which immigrant organizations they came from, the different organizations that were involved and how and when interpreters were used (see Methods, section Respondents, page 6-7)

Comment 8
Ad p 6, group discussions or FGD? Provide ref to the methods used.
Reply 8
We gave references in the method section and discussed some of its strengths as well (Methods, section Data collection, page 9).

Comment 9
Ad p 6, also re interpreters: were they included in the n of the sample?
Reply 9
This was indeed a confusing part of the method. We mentioned now in the method section that interpreters were included in the N of the sample. We introduced the inclusion of the interpreters in the section on Respondents (end of page 7) and discussed further their specific contribution (Method, section on Data collection, page 8).

Comment 10
Ad p 7: were interviews translated and then transcribed? Who did the translations?
Reply 10
We mentioned in the method section that interviews were transcribed but due to time restraints they have not been translated (section Data collection, end of page 9).
Comment 11
Ad p 7: would interviewees or study participants or respondents (you use this term on p 9) not be a better term than patients (because it is not clear what kind of patients they are or were).

Reply 11
Yes the reviewer is right. We replaced the term ‘patient’ with the term ‘respondents’ throughout the whole manuscript.

Comment 12
Ad p 9: If there are three things I tell two: what does this mean?

Reply 12
We explained was what meant here in the paragraph following the fragment (Result, the section on Situation 1: Respondents felt that exchange of information was inadequate, begin of page 13).

Comment 13
Ad p 9: spell out ER emergency room

Reply 13
We wrote emergency room now (Results, the section on Situation 2: Respondents experienced a difference in expectations between themselves and care providers about medical procedures, end of page 14).

Comment 14
Ad p 11 ‘different illness perception…’: sounds sophisticated. Is it the patient who uses these terms?

Reply 14
This was a highly educated respondent. We mentioned this now in the manuscript. (Results, Section on Situation 3: Respondents felt excluded from optimal care because care providers were prejudiced or discriminate, end of page 16).

Comment 15
“(I:…) means probably that the interpreter is throwing this in; should be spelled out.

Reply 15
We spelled both Interviewer and Interpreter out in the fragment in the section in Situation 1: Respondents felt that exchange of information was inadequate (page 13), and in the fragment in the section in Situation 3: Respondents felt excluded from optimal care because care providers were prejudiced or discriminate (page 16).

Comment 16
Ad p 12: our results clarify: why not simply “show”?

Reply 16
We rewrote the Discussion (page 17-21) and have deleted this sentence entirely

Comment 17
Ad p 14: “within the hospital” one? Many? Which one(s)? what types of?

Reply 17
We have not asked respondents about specific hospitals, or about types of hospitals. We mainly asked generally about their experiences with hospital care and our
findings therefore are also quite general, and do not allow us to say anything about specific care, for example about gynaecological care. We have added that our findings are most likely also true for ambulant care, given their general nature (Discussion, end of page 20).

Comment 18
Ad p 14: “future research”: future research is mentioned four times in this section: too much!
Reply 18
Yes you are right! We deleted the majority of this paragraph, restricting us to one suggestion for future research (Discussion, end of page 20).

Comment 19
Ad p 15: namely felt language problems: this aspect should be dealt with more explicitly in the results and discussion section.
Reply 19
We discussed into more detail how communication problems may be of influence on having low trust (Discussion, page 18).

Reviewer: Patricia Hudelson
Comment 1
This manuscript provides descriptive results from a study involving 4 face-to-face interviews, 3 telephone interviews, and 2 (or 3?) group interviews. The study explores immigrant patients’ experiences of hospital care, in an effort to identify factors leading to patient mistrust. The topic is widely relevant and of potential interest to many readers of BMC Health Services Research. The data appears to be quite rich despite the small number of interviews, and I strongly encourage the authors to further develop their analyses so as to fully exploit their data.
Reply 1
We analyzed our interview data into more extent in order to develop a more fully understanding of the concept of low trust. In the result section we have presented some more fragments of the interviews to show some more of the richness of the data, for example we added the fragment in the section in Situation 1: Respondents felt that exchange of information was inadequate (page 13), and the fragment in the section in Situation 3: Respondents felt excluded from optimal care because care providers were prejudiced or discriminate (page 16).

Comment 2
1) Major Compulsory Revisions
a) Under Background, trust is presented as “reflecting” or “including” various things, but I would have liked a clearer discussion of the operationalization of the concept (by others), and perhaps of variations in its definition by those who work in this field. This would then allow the reader to make sense of how you went from the definition to your interview questions.
Reply 2
We gave a more elaborated definition of trust as well as an operationalization by other authors in the introduction (page 3-4).

Comment 3
b) I think the paper would benefit from more conceptual clarity regarding the use of the term “ethnic minority”. The authors cite American studies involving ethnicity, but in the USA ethnicity is poorly defined and is also a self-identified characteristic. The authors refer only to place of birth (respondents’ or respondents’ parents). I wonder if it doesn’t make more sense to talk about immigration status, since the authors themselves say that most respondents were first-generation immigrants.

**Reply 3**

In the Netherlands it is common to define ethnic origin according to country of birth. We therefore referred in the method section (section Respondents, page 9) to an article explaining this (Stronks K, Kulu-Glasgow I, Agyemang C: The utility of ‘country of birth’ for the classification of ethnic groups in health research: the Dutch experience. Ethn Health 2009, 14(3):1-14).

We believe you are right that it makes more sense to speak about immigrants, and we therefore believe that the term ‘immigrants’ make more sense in an international setting, we therefore changed that throughout the manuscript.

**Comment 4**

c) The Methods section should be expanded to include a full description of the analysis process, including a description of the framework and charting methods. Who read the interviews? How was coding done? Independently or as a group? How were discrepancies identified/resolved? Who coded the data? How were data coded? (by hand, with software).

i) The authors should also provide the codebook (list of codes with examples) used to analyze their data.

ii) I also think the authors could include the interview guide as a box or table.

iii) I was not clear about whether there were 2 or 3 group interviews. 2 groups with Turkish patients were mentioned, then later there is mention of a group with 2 Chinese respondents.

**Reply 4**

We gave an elaborated description of the analytical process in the method section, in the part on Data Analysis (page 8-9). And furthermore:

i) we provided a codebook at the end of the manuscript (Box 3, page 35-36).

ii) we included the interview guide as well at the end of the manuscript (Box 2, page 35).

iii) We clarified that there were two Turkish group interviews and that the 2 Chinese respondents were interviewed separately (first part of Methods; Respondents, page 8).

**Comment 5**

d) Under “Respondents”, I think it would be clearer to say that “respondents included a convenience sample of 23 immigrant patients…”. To say here that you interviewed 23 people sounds like you had 23 interviews, which is not the case. In fact, you conducted 9 or 10 interviews (7 face-to-face, plus 2 or 3 group interviews).

**Reply 5**

The reviewer is completely right. We changed the sentence into “respondents included a convenience sample of 23 immigrant patients…” (See first sentence of Section Respondents, page 6) and we changed the sentence about the amount of
interviews to 11 interviews in total (9 individual and 2 group interviews) (Data Collection, first sentences, page 8).

Comment 6
e) In the results section, I wouldn’t refer to the 3 types of situations as “patterns”. Rather, they are 3 sources of mistrust or types of situations where mistrust was felt, as described by respondents.

Reply 6
We changed the term ‘pattern’ into the term ‘type of situation’ throughout the manuscript (abstract, result section and discussion).

Comment 7
f) The results section should include an overview of results, perhaps in the form of tables (for example, codes by interview). One doesn’t really have any feeling for the full range of issues mentioned, nor the importance/frequency of the different issues mentioned.

Reply 7
We gave an overview now of the different codes we used, with an example of a matching fragment (end of manuscript, Box 2, page 35). We also included some more statements in the result section about importance and frequency of the different issues that were mentioned. Finally, we provided a box with a table of respondents’ characteristics by interview method and their description of critical incident, as to provide more insight in the full range of issues that were mentioned (see end of manuscript, box 1, page 27).

Comment 8
i) What sorts of factors were discussed by which interviewees? Were there any differences between the group vs. individual interviews? Between different nationalities? What were the most salient issues mentioned by respondents?

Reply 8
We have given a more detailed description of who said what (section Data collection, p. 8 -9 and an extra box on page 27). We also have added after the quotations of fragments of the interviews, the reference to the specific respondent, so that he/she can be found in this box. There was one difference between group vs individual interviews, and we described that the type 2 Situation was primarily experienced by participants of the Turkish focus-groups, although other participants referred briefly to it as well (end of page 14). This seems also be the only difference between ethnic groups. We discussed the possible effect of this in the Discussion, section Strengths and Limitations, page 20.

Comment 9
ii) A table of respondent characteristics by interview method would be helpful (nationality, age, sex, migration status, etc.)

Reply 9
At the end of the manuscript we gave an overview of the different respondent characteristics by interview method and description of critical incident. See Box 1 on page 27.

Comment 10
g) Discussion: I feel the paper would be greatly strengthened by a more indepth discussion of the significance of results. What does this paper add to the existing literature on language/cultural diversity and their importance for quality of care and patient safety?

Reply 10
We have discussed now into more detail what our paper add to the existing literature on trust (page 18). We have also elaborated on how our findings may be used in education, relating to the existing literature on cultural competences (page 21). We are aware that we also may discuss our findings in relation to language/cultural diversity, quality of care and patient safety. We, discussed very briefly what our findings could mean for the quality of care (page 19), but our findings do not allow us to discuss these issues into great extent. It is very hard to say how taking into account our findings will improve concretely the quality of care. A quantitative study could relate patient trust to instrumental variables such as use of preventive services, adherence, and continued enrolment.

Comment 11
h) There is no discussion of the study weaknesses. In particular, what are the potential drawbacks of the mixed methods and convenience sampling used in the study?

Reply 11
We elaborated on possible limitations with regard to our use of mixed methods and the convenience sample in the Discussion, Section Strengths and Limitations, page 19-21.

Comment 12
i) The manuscript would benefit from review by an English native-speaker.

Reply 12
We sent the paper to a professional proof reader who has made several corrections (in red), and hope that the English we used in the paper is now correct.

Comment 13
A few specific examples:

i) I think the title could be improved. One option might be “Low level of trust among hospitalized immigrant (or ethnic minority) patients” Or “Factors affecting trust among hospitalized immigrant patients: a qualitative study”. However, I have replaced the authors’ word “in-hospital” with “hospitalized” but am not sure this is correct. Did all respondents describe experiences while hospitalized, or were there examples of mistrust during ambulatory care as well? If the latter is the case, then the title would need to be changed to reflect this. For example “Health care experiences of immigrant patients: a qualitative study of factors affecting feelings of trust” or something like that.

Reply: We changed the title into: Health care experiences of immigrant patients: a qualitative study of factors affecting feelings of trust.

i) “Presumptions” should be replaced by “prejudice”

Reply: we changed this throughout the whole manuscript

iii) There are many places where commas have been used inappropriately;

Reply: we hope that this is correct now

iv) There are also a number of instances where sentence structure sounds a bit non-English.
Reply: We sent the paper to a professional proof reader who has made several corrections (in red), and hope that the English we used in the paper is now correct.

Reviewer: Irena Papadopoulos

Comment 1
The article did not live up to my expectations. In my view more clarity needs to be provided regarding the methodology; for example: different approaches to data collection are mentioned such as face to face interviews, telephone interviews, interviews using the voice of a daughter, focus groups. The authors need to discuss the effects their approaches had on the quality and nature of the data they collected.

Reply 1
We discussed the use of mixed methods now in the methods section (Section on Data collection, page 19), as well as in the discussion, in the section about the strengths and limitations of the study (page 20).

Comment 2
There is also a predominance of Turkish women in the sample (14 out of 23 or it could be 22 if the interpreter is not counted). What effect has this had?

Reply 2
In the discussion (in the paragraph about the strengths and limitations, page 20) we discussed the possible effect of the predominance of Turkish women.

Comment 3
We need to be told how many of the participants were women and how many were men; does gender have any effect on the analysis? The ethnic make up of the sample is not given either (other than 14 of them are Turkish women). This is important and I expected the analysis to tease out the gender and ethnicity angles.

Reply 3
At the end of the manuscript we now provided a table of respondent characteristics by interview method, including gender (Box 1 on page 27). The point you make about teasing out the gender and ethnicity angles is a very interesting one. We, however, would like to restrict ourselves to ethnic background of the respondents, or more precisely to their migrant background. From our results we cannot conclude how the particular ethnic background of a respondent was of influence on low trust. We can only make general points about the influence of language, differences in expectations and feelings of prejudice. To tease out the influence of different ethnic backgrounds would ask for a more quantitative approach. Furthermore, for the respondents themselves their low trust was not related to the specific type of hospital care, such as gynaecology, nor to the gender of their care provider, but to the patterns as we described in the manuscript.

Comment 4
The authors also should report how many of the participants were interviewed in their own language and how many in Dutch and discuss the impact of using interpreters to collect data particularly as they decided to include the experiences of one of the interpreter which were shared during data collection.
Reply 4
In Box 1 at the end of the manuscript on page 27 we also described how many of the participants were interviewed in their own language and how many in Dutch. We discussed the use of the interpreters in the method section and described how their presence created a safe atmosphere for the participants of the group interviews (Section on Data Collection, page 8). We described now that one interpreter obviously felt safe herself to share her experiences with the group (page 7). The other interpreter recalled a critical incident of someone else who did not want to be interviewed herself (page 7). As we conclude in the Discussion, in the section on Strengths and Limitations, we describe that mainly because we were flexible with our methods that we were able to provide a safe environment for respondents, to discuss painful experiences which resulted in extensive data (page 20).

Comment 5
The themes are repeated several times and the discussion repeats the results. The discussion should provide a more robust theoretical reference to what the results mean rather than the rather superficial one with numerous sweeping statements such as 'the study provides insights into conditions in hospitals that are destructive to trust' which in my view is not adequately evidenced in the results section.

Reply 5
We rewrote the discussion so that more attention is paid to what the results mean, first in relation to the concept of trust (page 18) and in relation to other research about trust (page 18) and second in relation to practical consequences (page 18; page 21).

Comment 6
Level of interest: An article of limited interest
Quality of written English: Needs some language corrections before being published

Reply 6
We think that the rewritten manuscript is now more adequately addressing the concept of low trust and how this is experienced by immigrant patients. We believe that the manuscript is now of more interest. We also sent the paper to a professional proof reader who has made several corrections in red and hope that the English we used in the paper is now correct.