Author’s response to reviews

Title: Written narratives from immigrants following a prenatal diagnosis: qualitative exploratory study

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Version: 1 Date: 15 Jan 2019

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Dear Editor and Reviewers,

Thank you for giving us the opportunity to revise the manuscript entitled “Written narratives from immigrants following a prenatal diagnosis: qualitative exploratory study”, submitted to BMC Pregnancy and Childbirth (PRCH-D-18-00529). The comments from editor and reviewers were very valuable to improve the manuscript. Please see responses to specific comments below.

EDITORS COMMENTS

Editorial Issues:

This needs a good English editor to check for syntax and parallelism issues. It is relatively well written, however there are many places where the plural is used incorrectly or where minor syntax problems give an English-reader pause. Even in the abstract and beginning, the term is exploratory research rather than explorative. There are multiple instances of incorrect plural usage (e.g. In the abstract: "The experiences of insufficient and incomprehensible information calls attention to the importance of tailored approaches and use of adequate translating services." Should recognize that 'experiences…call' (not calls). There are MANY instances of this type of error. As noted above, I believe more literature could be cited, and maybe a bit less of the author's own.

We have added references and have checked the language with the aid of language editors.

REVIEWER 1.
The fact that this sample is so small after a recruitment including 26 women's centers, even though only 10 responded, makes this reviewer wonder how biased this sample is. Ideally, recruitment would have occurred over a longer period and snowball sampling may have been useful. Regardless, we have the sample that we have, and it does provide support for some of the concerns discussed in the findings and discussion.

We agree and have expanded the methodological discussion in the revised manuscript.

I believe reflexivity statements can be important for interpretive work, though I do not believe this analysis rises to the level of interpretive work, so a reflexivity statement is not as necessary. Nevertheless, this would not fit the bill to be a reflexivity statement as it includes no true reflexive statements, merely a description of the authors' positionality.

We have deleted the section previously referred to as reflexivity.

In regard to the sample characteristics, it would be useful to know how religion played a role too. Both the fact of the language spoken and some of the quotes indicate that the women (may all) were Muslim and therefore may have had differing thoughts about termination for fetal anomaly that were influenced by their belief systems.

We agree with you that religion may have influenced the decision concerning whether or not to terminate the pregnancy. Unfortunately, we did not include any question about religion and can thus only speculate with regard to religion. We have added a section in the discussion about this topic.

Likewise, we do not know whether the interpreters (or were they really just translators?) had any influences that led them to inhibit or modify their communications when translating with the health providers and the women in the sample. It is worth making clear the distinction between translation services and interpretation services.

We have added information about the distinction between translation and interpretation services.

Another issue that the authors do not grapple with at all, whether through recognition of the limitations of their method of recruitment and data collection or through discussion of the issue in the Discussion is the low literacy rates among Arabic refugees. Perhaps Sweden got only the "cream of the crop," but most countries' Arabic and Sorani speaking immigrants have a fairly low rate of reading and writing literacy skills, meaning that the respondents are likely the most highly functioning among the group the authors see them as representing. This too should be made clear, and the methods for conveying information must be interrogated for being able to reach and explain to women who have low literacy skills (and who often will hide the fact that they are unable to read even in their own language).

We agree with you and have added a discussion concerning health literacy in the revised manuscript.
The findings section seemed very thin and contradictory to me. I prefer more data extracts (quotes) with richer description. Of course the women were overcome by emotion as this is almost always a shock as most women expect to have a 'bonding experience' rather than learn there is a fetal anomaly.

We have now included more quotes in the result section.

There is a robust literature in that arena and the authors chose to cite much of their own work rather than to draw on the very robust literature about emotional responses to a diagnosis of fetal anomaly or of the bereavement response after a termination, if elected. Likewise, the burdens of continuing a pregnancy has a fairly rich literature base as well. More drawing upon that rich literature would be useful, especially if there is anything about Arabic, Muslim or Kurdish women and prenatal diagnosis.

We have now included other references in the manuscript.

The findings also seem contradictory. Although many experienced the "hurricane of emotion," it seems respondent 3 was actually expecting Down syndrome and seemed relatively unfazed, according to her quote. Likewise, several quotes describe having a disturbing lack of information about the diagnosis (and maybe even getting mis-information through the interpreter) as well as during the termination procedure, yet the next theme praises the health providers and system. There needs to be better description of how these women made their terrible experiences of lacking information fit with a positive assessment of the care received.

We have expanded the findings and discussion according to your suggestions.

The inability to go back to get further clarification of responses, despite the purported aim to "get insights" (a phrase used much too frequently), means that it seems a bit thin. Nevertheless, the fact that women were not fully informed before making life altering choices about whether to continue a pregnancy affected by fetal anomaly makes this reader feel this manuscript illustrates such an important point that it should be published. Therefore, expanding those findings and enhancing discussion of the implications of poor translation experiences seems justified.

We have revised the manuscript according to your suggestions and hope that the changes improve the manuscript.

I believe the issues of literacy and lack of information about the interpreter/translation experience are critical limitations. Although the authors believe the anonymous web environment is a strength, I deem it a limitation as it excludes low-literacy respondents and does not allow for deeper responses or ongoing interactions.

We agree that the chosen data collection may hinder recruitment of persons with low health literacy and have added a discussion about this important aspect in the manuscript.

REVIEWER 2
Most of the findings are not at all novel. I accept there can be value in seeing if findings from minority populations are the same as those in the established literature, but it would have been remarkable indeed if the participants in this study had not experienced ‘unexpected emotional shock’, sadness, sorrow, sleep difficulties and similar reactions.

We agree with you and have revised the manuscript accordingly. We hope that the changes clarify how the findings translate in relation to other research.

Second, the likely effect of the methods used on the composition of the sample and some of the views expressed is insufficiently discussed. The advantages of the chosen method are listed in some detail, but self-selection of more educated people, who are comfortable in describing their emotional experiences using the written word has almost certainly taken place, and the potential effect of this on the results needs to be acknowledged. A less educated sample might, for example, have had greater problems (or fewer, if their expectations were lower), and these kinds of biases need to be openly acknowledged.

We agree and have added text concerning this aspect the methodological discussion.

The authors make some interesting points about translated medical information, both in terms of informing choice about the future of the pregnancy and what to expect from undergoing a termination. Presumably standardised information could be prepared for the latter in multiple languages, but probably not for the former because of the variation in diagnoses, but these more novel aspects of the work get lost in the rest of the findings.

We have revised the manuscript according to your suggestions.

On the subject of good information, I was disappointed to see that the Korenromp group's findings about the psychological aftermath of termination of pregnancy were selectively reported: the majority of women had no regrets about having a termination despite experiencing heartache and distress, but only the latter is mentioned here.

We have added text about this in the revised manuscript.

Finally, I would have appreciated a few more details of the antenatal care provided in Sweden, particularly in relation to the timing of the scan. In the UK, for example, most women have both a first and second trimester scan, which have different implications for subsequent management.

We agree and have included more details about the Swedish context.