Author's response to reviews

**Title:** Challenges in the Care for Consanguineous Couples: an Explorative Interview Study among General Practitioners and Midwives

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**Author's response to reviews:** see over
June 14th, 2012

To the Editor: dr. Hein van Hout

Dear dr. Van Hout,

Thank you for your e-mail d.d. 30 July. We were very pleased to receive the comments of both referees on our manuscript entitled “Challenges in the Care for Consanguineous Couples; an exploratory interview study among general practitioners and midwives”.

Please find enclosed the revised version of the manuscript in which we have addressed those comments. You will find our answers to the reviewers attached to this letter.

We hope that our adjustments are satisfactory.

Additionally, we would like to state that this study adheres to the RATS guidelines on qualitative research.

We look forward to hearing from you at your earliest convenience.

Sincerely,

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Referee 1, Alan Bittles

1. Title: ‘An exploratory interview study’ would be more appropriate than ‘an explorative interview study’.

Thank you for this suggestion, we have changed it accordingly.

2. It would be helpful if some comment was included in the Methods or in Table 1 regarding the birthplace and/or ethnicity of the study group.

We have added some information about this to the paragraph on study design and participants (see also referee #2).

3. p. 7, para 5 ‘..their clients refrain from taking further steps and thus the topic of consanguinity is set aside’.

This phrase is rather ambiguous and could benefit from further clarification. For example: i) Do the clients refrain from taking further steps because they expect that the midwife or GP will pursue the topic of prenatal diagnosis, or that they (the clients) would not wish to follow this line of discussion without first involving senior family members? ii) Why ‘set aside the topic of consanguinity’ because of a perceived lack of follow-up from the client with respect to prenatal diagnosis?

This stance suggests some sensitivity on the part of the study group with respect to consanguinity, and a reluctance to become too closely involved in discussions on the topic.

We have tried to clarify the meaning of this paragraph and made some changes. i): The younger generation is willing to discuss risks and reproductive options, but after discussing it with their primary care professional they will not go through with the procedure. Reasons respondents mentioned were similar to the beliefs mentioned in the previous part – influence of family/community and influence of religious beliefs. Naturally, these are all beliefs of the professionals and it would be very interesting to investigate the beliefs and attitudes of the clients.

Regarding ii) in this context we did not mean to suggest that the subject is just ‘set aside’, especially because there is a positive development according to the professionals regarding the younger women who are willing to discuss the subject. We have rephrased the sentence, hopefully to your satisfaction.

Minor essential revisions

1. p. 9, para 4 ‘..most participants admitted they believed consanguinity to be not done’. The current meaning of this phrase is unclear. Do you mean ‘they believed consanguinity to be undesirable’? or ‘they believed consanguinity should be avoided’?
Not done is apparently a typical Dutch invention, meaning ‘inappropriate’. We have changed the sentence accordingly (see also referee #2).

2. References 6, 11 and 12 are incomplete.
We’ve completed these references and updated two others who were published in the meantime (1. Ten Kate & 2. Hamamy).

Referee 2, Hanan Hamamy

1. In the abstract and for international readers, it would be recommended to mention that the study was conducted in Netherlands;
We have added this to the abstract.

2. Introduction section: First sentence in second paragraph should read: It is well known that a higher risk of congenital disorders is present in children of consanguineous parents, with a reported average increased risk of 1.7 – 2.8% for the offspring of first-cousin couples over the baseline 2-3% risk in the general population.
We have changed this paragraph accordingly.

3. The authors could possibly give a general background on preconception care facilities in the Netherlands and whether professionals address in anyway the 2-3% risk of congenital disorders expected in any pregnancy.
We have added some information to the introduction, p.3 last paragraph.

4. In the section on study design and participants, did any of the participants share a similar culture to the consanguineous couples?
Yes, we interviewed one midwife from a Moroccan background, we have added this as a comment in the paragraph ‘study design and participants’. (see also referee #1)

5. In the results section, on the “Beliefs about consanguineous couples’ religious and social values”, the authors give a number of quotes from the participants as heard or felt in their session with a consanguineous couple. It could be noteworthy to indicate approximately how often the participants see consanguineous couples in their care and whether the questionnaire included a question on number of consanguineous couples seen by each participant?
The problem of language barrier is well emphasized in this section.
We have added the estimates that were given to us by the professionals to the information given after each quote. Naturally, we could not base these estimates on actual numbers.

6. Under the heading of “Topic’s sensitivity”, the term “not done” in referring to consanguineous couples is not understood in this sentence “most participants
admitted they believed consanguinity to be not done."

We have changed the term to the original meaning, ‘inappropriate’ (see also referee #1)