Author’s response to reviews

Title: Few women received a specific explanation of stillbirth - an online survey of women’s perceptions and thoughts about the cause of their baby’s death

Authors:

Berit Höglund (berit.hoglund@kbh.uu.se)

Ingela Rådestad (ingela.radestad@shh.se)

Ingegerd Hildingsson (ingegerd.hildingsson@kbh.uu.se)

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Author’s response to reviews:

Reviewers comments

Reviewer 1

1. 356 women participated and none were excluded. It should be clear that none were excluded (however, that is unusual since women often complete surveys that they are not technically eligible for eg they were 26 or 27 weeks gestation for example). But OK if it's true. More importantly, in the discussion a limitation is that this is only a proportion of the stillbirths that occurred during that time frame and the participants may or may not be representative sample of the true population.

To comply, and have inserted a paragraph in the Method section:

We have also inserted a paragraph in the discussion section, strengths and limitations:

“From the original survey none eligible responses were deleted prior to the analysis (births before 2010 birth gestational week< 28)”

“To get more robust data the data collection was restricted to five years in order to minimize recall bias. However, this is only a proportion of the stillbirths that occurred during that time frame and the participants may or may not be representative sample of the true population.”

2. I still think that the issue of lack of demographics should be expanded upon. Typically a "Table 1" would include things like maternal age, gestational age, parity etc etc. These are important variables and if they are not available it should be more throughly discussed in context.
The only information available was lengths of gestation and year of stillbirth. To comply, we have inserted a paragraph in the methodological consideration section.

"We lack information about background data such as age and parity as the survey was anonymously.”

3. The limitations section regarding preterm/term and recent/more remote stillbirths is worthy of more detailed discussion. Particularly since parents of more recent stillbirths may not have had/been able to digest all of the information yet. This is touched on but certainly worthy of additional comment.

To comply, we have inserted a paragraph in the discussion section, strengths and limitations.

“Notably, it is possible, since parents of more recent stillbirths may not have had/been able to digest all of the information yet, their experiences might have been affected. However, the women’s responses of reasons of stillbirths correspond well with other studies (20).”

4. The report of "SIDS" is the perfect example of misperceptions. I understand that the authors are just reporting what the mother said despite that it is highly unlikely any provider would say this. But this issue could be used in the discussion to highlight the point that while maternal report is clearly needed, the lack of correlation with what was actually said is a limitation. This is true. The findings are only based on women’s self-report. A paragraph was inserted in the discussion section, strengths and limitations.

“One example of this is the notion of ‘SIDS’, which is not an accurate definition in terms of stillbirth.”

5. Although the authors state that they have now only used "some" and "many" sparingly, these words are not helpful. Please let the reader know the proportion of women who reported the concerns. This will strengthen the manuscript and allow the reader to put things into context. Regarding self blame and blaming staff, it would be very helpful to list this numbers. Readers will want to know this information.

In the result section the proportion of responses to all questions are presented. To comply, we have excluded “some” and “many” from the manuscript and inserted numbers when appropriated-
6. The appendices are now improved. In the manuscript it would be helpful to state that 16% of women had multiple reasons for stillbirth

We do not understand this comment.

7. The authors added "Other limitations were that women's perceptions of the care that they received were investigated, not necessarily the care that the healthcare staff provided" although I am not entirely sure what this means. Can this be clarified? To comply, we have omitted the sentence and we try to clarify with an inserted sentence in the method section, strength and limitation.

“We have no access or information from the hospitals where the women with stillbirths were taken care of. Caregivers might have given other explanations to the women about the cause of their baby’s death. However, in this study we investigate how the women have interpreted the given information.”

Reviewer 2 (Reviewer 3)

The presentations of sampling process i.e. definition of study population and sample is not clear. How did the authors verify that the women had stillbirths? Has the questions/tool pre-tested or standardised? In the whole method section, authors even do not mention the sample size.

The sample size is presented in the result section: “Of the 356 women in the sample…..”

To comply, we have added information about the sample in the method section.

We could not verify that the woman had stillbirths. However, responses with unreliable comments were excluded.

The survey contained study specific questions based on a previous survey and clinical experiences. The questions have been tested (face-to-face validity). To comply, we have added a sentence about this in the method section.

“The sample consisted of women with self-reported stillbirth after 28 weeks of gestation, in the period between January 2010 and April 2014.”

“The study specific questionnaire was developed based on a previous survey and clinical experiences. The questions have been tested, face-to-face validity.”
Also the results did not give sample characteristics (background socio demographic) which is so common in most of the articles.

The only information available was lengths of gestation and year of stillbirth. To comply, we have inserted a paragraph in the methodological consideration section.

"We lack information about background data such as age and parity as the survey was anonymously."

Title need to be revised to incorporate the main objective: whether explanation for stillbirth received or not as well as the women's thought.

A new title is inserted.

"Few women received a certain explanation of stillbirth - an online survey of women’s perceptions and thoughts."

Abstract: Please name the software used in online survey.

To comply, we have inserted information about the software in abstract.

The survey was provided by the company Impera in Sweden.

What is certain and uncertain explanation?

To comply, we have added information to clarify certain and uncertain explanation in the Result section.

“In an uncertain explanation the woman used the words probably, presumably and likely, further a certain explanation had a clear indubitable message.”

Please state the exact amount 'many of themŠ.othersŠand Šstill othersŠ."

These expressions refer to the qualitative parts of the survey (e.g. the open ended questions). There is no way to link the open-ended questions to any individual. When categorising qualitative content it is not appropriate to give the exact amount of responses in each category.
Conclusion needs to be revised with implications. At present, it is no more than repetition of the results.

A paragraph has been inserted in conclusion section.

“In addition caregivers need to be aware of their communication regarding the explanations of the cause of stillbirth and to clearly frame their messages in order to avoid misinterpretations.”

Background: Stillbirth needs to be defined in the background and the opening sentence needs to be revised.

Inserted an opening sentence and a definition of stillbirth is defined.

“Stillbirth affects women during lifetime. Stillbirth is defined as the death of a baby in utero after 22 completed gestational weeks (1).”

Methods: I do not know whether the journal has the instruction to keep the objectives in Methods. Otherwise, the usual sequence is at the last paragraph of background after having identified the need for investigation.

Changed: The aim is moved to the last paragraph of background.

Better to name the online survey used; and approach of qualitative data gathering.

The survey was provided by the company Impera in Sweden and a mixed method design was used.

“Data was collected through an online survey provided by the company Impera in Sweden and hosted by Swedish National Infant Foundation (11) and placed on the Foundations homepage. The foundation supports parents after stillbirth and is a member organization of the International Stillbirth Alliance (ISA). The participants were self-recruited after being informed about the study through newspapers, Facebook, and newsletters within the organisation. The approach of qualitative data gathering was a mixed method design.”

Sample: "All women in the sample had experienced stillbirth after 28 weeks of gestation between January 2010 and April 2014." Not clear what authors want to convey: is it how they choose sample or inclusion criteria?

This sentence has been clarified in the Method section.
“From the original survey none eligible responses were deleted prior to the analysis (births before 2010 birth gestational week< 28). The sample consisted of women with self-reported stillbirth after 28 weeks of gestation, in the period between January 2010 and April 2014.”

Data collection: Does this online survey cover all over Sweden?

Yes, it was an open survey. We have added information in the method section.

“…..this online survey cover all over Sweden.”

For which period of stillbirths?

Jan 2010 to April 2014, we have clarified that in the Method section.

How did the authors confirm that the women had stillbirths?

The survey was anonymous and there was no way to confirm this.

Any source to validate?

The validating source was related to the previous study, we have added a reference: Stormdal Bring H, Hulthén Varli IA, Kublickas M, Papadogiannakis N, Pettersson K. Causes of stillbirth at different gestational ages in singleton pregnancies. Acta Obstetrica et Gynecologica Scandinavica. 2014;93:86-92

How did the authors compose 87 questions, what is about their validity and realiability? Is it standardised? No mention in the method.

The survey contained study specific questions based on a previous survey and clinical experiences. The questions have been tested (face-to-face validity). To comply, we have added a sentence about this in the method section.

The study specific questionnaire was developed based on a previous survey and clinical experiences. The questions have been tested; face-to-face validity.”
Out of 87 questions, did the authors used only four questions? Other questions will be presented elsewhere.

Please clarify further what is meant by certain explanation and not a certain explanation. Who decides which is certain and which is uncertain, and how?

To comply, we have added information to clarify certain and uncertain explanation in the Result section.

“In an uncertain explanation the woman used the words probably, presumably and likely, further a certain explanation had a clear indubitable message.”

It is better to say 'open question' rather than unlimited space for response.

Changed to: Two other questions were open for responses (i.e. “What explanation did you receive about the baby’s death” and “What are your thoughts about why the stillbirth occurred?”)

Analysis: Into how many domains/specific topics the text material was divided?

Five domains. We have clarified in the Method section.

“five”

Analysis do not mention about descriptive statistics. This has been inserted in the analysis section.

“Descriptive statistics was used to present numeric data”

Results: It makes no sense: Years of the stillbirths ranged from 2010 to 2014 (mean: 2011; median: 2011).

Mean: 2011; median: 2011 have been deleted.
Explanation of cause of death: Did the 116 women received a certain explanation or an uncertain explanation. Before it was stated that "84 (23.6%) reported receiving a certain explanation, and 99 (27.8%) reported receiving an uncertain explanation."

This is a misunderstanding and is the number of women completed the open-ended question.

Women's thoughts on the cause of their baby's death:

"Most women (n = 199, 56%) reported their thoughts on what might have caused their baby’s death", so did it indicate the rest had no thoughts? They could also been satisfied with the explanation they received.

Please use inverted comma to state women's own words.

Fulfilled.

Changed to inverted comma to state women’s own words.

Discussion: It should start by summarising all findings. The opening sentence does not summarise all findings, for example women's thoughts of cause of death.

Done.

Conclusion: "A third of women in the sample received an explanation of their baby’s death", is it a certain or uncertain explanation? The conclusion has been reworded.

“Nearly half of the women did not receive a clear explanation of the reason of their baby’s death.”

Need to include some suggestion based on the findings for the delivery care of Sweden.

Implications have been inserted.

“In addition caregivers need to be aware of their communication regarding the explanations of the cause of stillbirth and to clearly frame their messages in order to avoid misinterpretations.”