PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (see an example) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Bereaved parents' experience of stillbirth in UK hospitals: qualitative interview study
AUTHORS	Downe, Soo; Schmidt, Ellie; Kingdon, Carol; Heazell, Alexander

VERSION 1 - REVIEW

REVIEWER	Joanne Cacciatore, Arizona State University School of Social Work
REVIEW RETURNED	30-Oct-2012

THE STUDY	While some important references are cited, I'd highly recommend a more thorough and thoughtful introduction to the previous literature. There has been much written on the subject of stillbirth and management (think Spong's recent text, Stillbirth, with an entire chapter dedicated to psychosocial care). Also, the Lancet series dedicated to stillbirth is not even cited. These works should be relevant to a study such as this.
RESULTS & CONCLUSIONS	More exhaustive introduction is recommended.
GENERAL COMMENTS	A very important and relevant topic of study, this paper is sensitively written and thoughtful. The approach is client-centered and qualitative methods are appropriate for these rich data. In general, the paper is well-written. Areas lacking are the introduction, which seems too brief for the topic and seems to overlook some of the most seminal work in this area (i.e. Lancet series; Spong's text). I'd like to see a general overview of the current standards of care (treatment as usual) for women and families experiencing perinatal death included in the introduction as well.

REVIEWER	Siassakos, Dimitrios Southmead Hospital
REVIEW RETURNED	12-Nov-2012

GENERAL COMMENTS	This is a very interesting manuscript and an extremely useful study, but I believe the interpretation of the findings should be both more detailed and explicit but also balanced, avoiding biased over-interpretation and statements that are too strong and that healthcare staff might find insulting. After all, it might be staff's training that has failed them and patients, and not staff who have failed the patients. Please delete "incompetence", "abuse" etc. and try to offer a balanced interpretation of the findings on holding the baby, and this paper will become much stronger. Finally, please try to keep the Results to the actual findings, and move any subjective interpretation and judgments to the discussion. At present the Results are too long and the Discussion too thin, and

	it is difficult to determine where data stop and interpretation starts (which can happen with qualitative research, but I am not sure the limits should be as obscure as they are here).

VERSION 1 – AUTHOR RESPONSE

1. Reviewer: Joanne Cacciatore, Arizona State University School of Social Work

1.1 While some important references are cited, I'd highly recommend a more thorough and thoughtful introduction to the previous literature. There has been much written on the subject of stillbirth and management (think Spong's recent text, Stillbirth, with an entire chapter dedicated to psychosocial care). Also, the Lancet series dedicated to stillbirth is not even cited. These works should be relevant to a study such as this… Areas lacking are the introduction, which seems too brief for the topic and seems to overlook some of the most seminal work in this area (i.e. Lancet series; Spong's text). I'd like to see a general overview of the current standards of care (treatment as usual) for women and families experiencing perinatal death included in the introduction as well.

The introduction has been amended and extended. Explicit reference is made to the chapter on psychosocial care in Spong CY (2011) Stillbirth: Prediction, Prevention and Management. Blackwell Publishing Ltd, Chichester , The Lancet Stillbirth Series, and current international guidance from the Royal College of Obstetricians and Gynaecologists and the American College of Obstetricians and Gynaecologists. In addition, we now reference recent relevant papers from the USA and Sweden that have been published since our first submission.

2. Reviewer: Dimitrios Siassakos, NIHR Clinical Lecturer in Obstetrics, University of Bristol, UK

Competing interests:
- Funded by Sands to study bereavement care and training (InSight Study)
- Author of the RCOG guideline on stillbirth

2.1 I would like to see the detailed interview schedule as an appendix, to understand to what degree the findings were spontaneous or affected by the agenda - the "agenda" being an understandable aspect of qualitative research.

The interview guide has been added as APPENDIX 1 at the end of the manuscript and this letter.

2.2 I would like to see a Table where the frequency of each theme and sub-theme is mentioned: in how many of the interviews did it emerge as a theme? This quantitative approach cannot necessarily capture the impact of each theme and sub theme, but could be supplemented with qualitative observations - reflexive accounts and field notes from the interviews where it had been mentioned.

We have added some quantification (i.e. to clarify in the narrative that 'majority' equates to 23 out of 25 respondents). However, we have not done this as a table, and for each theme, as we believe this is counter to the epistemological basis of qualitative research. One of the cardinal intents of qualitative research is to derive theory based on emerging insights that may equally be derived from one respondent alone, or from all of the respondents in a specific study. As summed up by Pope and May (1995): '…the goal of qualitative research is the development of concepts…giving due emphasis to the meanings, experiences and views of all the participants… qualitative work is held to be inductive (moving from observation to hypothesis)…''. We do anticipate that any testing of the hypotheses arising from this study (for example, through the use of the emerging theories about the kind of staff education that may improve services in future) will include quantitative data, with a deductive intent. In accordance with current COREQ standards for reporting qualitative research we demonstrate the

consistency between the data and our findings in Table 2.

2.3 The authors need to remember that this was a qualitative study of patient perception. Perception is an approximation but not equal to reality, and strong statements of fact do not belong here. For example: "disregard evidenced" "emotional abuse" "revealed incompetence" are very strong statements, and it is not clear whether they reflect the participants' wording, or the authors' interpretation.

These three statements (on page 14/29 of the reviewed manuscript; lines 3,19,26) originate from segments of coded text that were used to identify emerging themes. They therefore reflect the authors' interpretation of experiences described by parents. The manuscript has been amended as follows:

• When these messages were poorly communicated, or inconsistent, or ['revealed incompetence' replaced with] led parents to question clinical judgment or skill, their sense of loss was augmented.
• The sentence 'In some cases staff exhibited a kind of casual inhumanity that amounted to emotional abuse' has been deleted, as readers can refer to box 3 to form their own views on these aspects of the data.
• Similarly, 'to the disregard evidenced in some parents accounts' has been deleted so the sentence now reads: 'In stark contrast, other respondents reported excellent, empathetic, competent, respectful, human and emotionally intelligent care.'

2.4 I have a strong philosophical, ethical, and scientific disagreement with the authors' over interpretation of the findings with regards to contact with the baby. First, the authors use several different wordings to describe the relevant findings and their interpretation:
"Some parents felt that staff could be more directive"
"the importance of supporting families to see and hold their baby"
"sensitivity about the best time to hold the baby"
"being persistent in offering the chance to hold the baby"
So, the authors contradict themselves whether staff should be supportive of parental wishes, or try to impose holding the baby which finds me ethically strongly opposed. This used to be the (patronising) standard of care a long long time ago and I thought patient-staff interaction has changed a lot since then.

We accept that our claims contradict current guidelines, but they are grounded in the data. These interpretations were independently and then collectively reached by three members of the research team (SD, ES, AH). The fourth member of the team (CK – who was on maternity leave during the analysis phase) has since returned to the data to independently verify the findings twice: once during the drafting of this paper, and again whilst formulating the response to these comments.

For example, the sentence 'This is an area where some parents felt that health care staff could be more directive' is grounded in the experiences of four women who especially welcomed their midwives taking control and persuading them to hold their babies (13,15,16,19) and four other women who felt staff should have done more to persuade them to do so (02,08,09,21). These women were very critical that staff had never "told us" that they could hold their baby again. They also identified the importance of contact with their baby, and the need for staff to strongly emphasise that they were more likely to benefit from it than not to do so, as the most important aspect of care to be fed back to healthcare professionals. None of the women criticised staff for persuading them to hold their baby when they did not initially want to do so. This detail has been added to the findings section of the manuscript and is commented on in the discussion. Indeed, very recently two published studies, one

from the US and one from Sweden, have reached the same conclusion as we do about the need for staff to be actively proactive in persuading women of the benefits of holding their baby, and we have added these references to the introduction and discussion. We have, however, changed the word 'directive' to 'assertive'.

We have also commented on the potential charge of being patronising. The women cited above clearly demonstrated that they changed their mind radically from their initial reluctance to hold their baby, to their later profound relief that they had been persuaded to do so. This seems to be a very complex area in which to deal with service user choice, as choices made around the time that parents are trying to deal with the shock of stillbirth may be deeply regretted later. From the data, we deduce that, for some women at least, being advised by staff who understand this is, in the end, a very important element in getting their one chance right. For us, this seems to be more about working in partnership with parents than about patronising them.

The RCOG guideline was developed by a multiprofessional group, underwent two internal and two external peer reviews including by clinical and lay experts, and the final wording was agreed by wide consensus and was carefully chosen (competing interest here as I am first author): "Carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed.". How is the RCOG guidelines "strong support" "in contrast with" the authors' "supporting families"? It is not, but it is indeed very different from being "persistent" or "directive". I wonder whether these sentences have come from different co-authors.

The relevant section of the discussion has been amended and now reads:

As noted in the introduction, the Royal College of Obstetricians and Gynaecologists12, and the American College of Obstetrics and Gynaecology13 have issued new guidance relating to the management of stillbirths. The RCOG guidelines state that “carers should avoid persuading parents to have contact with their stillborn baby, but should strongly support such desires when expressed (ref p.19).” Our data suggest that, for some parents at least, persuasion might, in fact, be appropriate. Some respondents explicitly praised members of staff who were directive about seeing and holding their baby, and a few were highly critical when staff did not repeatedly offer to facilitate this. These sentiments resonate with the 2010 SANDS campaign that led to an amendment to the wording of the NICE Guidance in this area30 , a very recently published focus group study including bereaved parents from the USA19, and an e-survey of 840 mothers experiences of seeing and holding their stillborn baby in Sweden20. The latter study reports that mothers felt more natural, comfortable and less frightened if staff supported ‘assumptive bonding’, where the baby was simply presented to the mother without asking her to choose. We suggest that when current guidelines are updated there is due consideration of this new research evidence, alongside cautious consideration of what it means to use terms such as “persuading”12 and “choice”30 in practice. Healthcare professionals are currently open to criticism for not encouraging parents enough, but that is not to say it is right for all mothers to be presented with their baby. This could be perceived as a return to paternalism. However, the alternative rhetoric of choice, in which service users are assumed to have the knowledge, responsibility and accountability in making decisions for themselves and their family with no awareness of the potential longer terms consequences, may also be contrary to good care practices 31 32.

In the tables, the experience of one woman is quite different from (some of) the authors' interpretations: "I was left to believe that because I wasn't ready to see her, that was final". This is very different: it implies that the offer of choice should not be prescriptive or terminal, but it does not seem to imply that doctors should impose their views either.

We have tried to address this comment in the paragraph above and added references to Mol (2008) and Kingdon et al (2009) on the complexities of choice and care in practice.

The ethical and philosophical arguments aside, scientifically the authors are basing their conclusions on "some respondents" in a qualitative study. We know and accept that in such studies the findings are influenced by the researchers and the design (so can we please see the schedule), so how can they make such strong statements?

The following sentence has been added to the manuscript:

Of the 25 participants in this study, 23 spontaneously talked about holding their baby. Only two women had to be prompted with the probe question ‘did you hold[your baby] (see interview schedule appendix 1).

2.5 Reference 15 is indeed an observational study thus prone to bias, but it is a controlled study of about 120 total women published in a leading journal, and I am not sure that the authors can refute the findings (or a national guideline developed by several experts) based on their personal interpretation of "some respondents" in interviews that could easily have been influenced. This section needs clarity in the supporting data, and a balanced unbiased (and consistent across the manuscript) interpretation please. "Sensitive" wording of the discussion, and an understanding that staff also have needs will also be helpful.

We hope the changes made to the discussion section and detailed in section 2.4 address this point.

2.6 This is a very interesting manuscript and an extremely useful study, but I believe the interpretation of the findings should be both more detailed and explicit but also balanced, avoiding biased over-interpretation and statements that are too strong and that healthcare staff might find insulting. After all, it might be staff's training that has failed them and patients, and not staff who have failed the patients. Please delete "incompetence", "abuse" etc. and try to offer a balanced interpretation of the findings on holding the baby, and this paper will become much stronger.

These terms have been deleted.

2.7 Finally, please try to keep the Results to the actual findings, and move any subjective interpretation and judgments to the discussion. At present the Results are too long and the Discussion too thin, and it is difficult to determine where data stop and interpretation starts (which can happen with qualitative research, but I am not sure the limits should be as obscure as they are here).

We have moved, added, or deleted sentences in the results and discussion sections.

We hope that our responses meet with your approval.
We look forward to hearing from you.

Yours sincerely

Professor Soo Downe (on behalf of all authors)

Pope C Mayes N 1995 Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research BMJ 311) 42-45

APPENDIX 1 (Web file only)

Interview topic guide: Bereaved parents' experiences of stillbirth in UK hospitals

Prior to each interview ES prepared a reference sheet listing what was already known about each family's experience of stillbirth so she could ensure the interviews were conducted as sensitively as possible. She also had the name and contact number of the local SANDS representative on this sheet to give to mothers and fathers if needed.

Following explanation of study, the interview process and written informed consent being obtained the interviewer sought to establish a rapport using unstructured dialogue based around the following opening sequence of questions (probes in italics).

1. Introduction
"Thank you for agreeing to this interview. I have read your answers to the on-line questionnaire, but this interview is an opportunity for you to say more, to help us understand in more detail, about what happened when your baby was born."

Can we start at the beginning; can you tell me the story of what happened when your baby [name] was born?
• What sort of pregnancy had it been? (straightforward/complicated)
• When did you find out about your baby's death?
• How did you learn your baby had died? Who was present?
• How far along in your pregnancy were you?
What happened after you had your baby?
• Did you see/hold/spend time with[name o f/ your baby]
• How did you feel immediately after birth?
• Have your feelings changed over time?
• Were the doctors or midwives able to tell you why your baby died?

2. Interactions with healthcare professionals

What was it like for you, interacting with different health care staff around the time [name of baby] was born?
• Where there any particular staff that you remember as influencing your care – for better or worse?
• In what ways?
• Were there certain members of staff that you relied on when you were in hospital?
• Did you see a bereavement midwife or counsellor?
• After you left hospital, did you have any further contact with any of the staff?
• With whom and when (i.e. subsequent pregnancy)?

3. Counselling and decision-making

How did hospital staff help you through such a difficult time?
• In what ways did staff support you after [name of baby] died?
• What were the things they did that were helpful?
• Can you explain why those things were particularly helpful?
• Was there anything they did that you found particularly upsetting?
• How do you think they could they have done things differently?
Some parents have told us that they found it very difficult to make decisions about things like funeral arrangements, or medical investigations to find out what caused the stillbirth. How did you go about making tough decisions like those?
• At what point did you know that there were decisions to make?
• Which decisions were the hardest to make?
• Was there anything that made those decisions easier or harder to make?

4. Post-mortem

One of the things we are particularly interested in is how parents decide about the tests to find out why their baby died. Can you tell me about the first-time a post-mortem was mentioned?
• What was your reaction?
• Was anyone or anything particularly influential in your decision as to whether to have a post-mortem or not?
• Did anyone have a strong opinion?
What information did you get about the options for tests that could be carried out?
• When was that information given to you?
• In what format?
• In what ways did you find that information helpful?
• Did you have any questions that went unanswered?
• How much time did you have before you had to make a final decision about which tests you wanted to have?
What were the most important factors that you took into consideration as you made your decision about a post-mortem for [name of baby]?
• What did you feel were the pros and cons?

Additional questions depending on interviewees responses to above, asked at interviewers discretion.

Can you give me a bit more detail about the key considerations for you?
• About the baby
• Cultural or religious
• Negative media attention (Bad press)
• Required transfer to another hospital
If had a post-mortem:
• How did you feel about the consent process and form you were asked to sign?
• How has having the post-mortem made a difference to your feelings?
• If subsequent pregnancies – How have the results of the post-mortem affected them?
How do you feel about having had the post-mortem now?

5. Summarising

To conclude, what advice would you give to doctors and midwives who care for people who have stillbirths in the future?

VERSION 2 – REVIEW

REVIEWER	Dimitrios Siassakos NIHR Clinical Lecturer, University of Bristol CoI as in previos review
REVIEW RETURNED	07-Dec-2012

THE STUDY	Qualitative study
GENERAL COMMENTS	This is a very important study and an interesting paper that is now more balanced and informative. All my comments have been addressed. The only minor exception is the reluctance to support the qualitative analysis with some explanatory simple statistics, as described in my previous peer review. I totally accept that this study was qualitative and numbers can even be construed by misleading, but I belong to those who believe there is overlap between inductive and deductive methods, and quantitative observations can add to (not replace!) the interpretation of qualitative studies the same way that qualitative observations or studies can add to RCTs. For example, the fact that 23 of 25 women spontaneously talked about holding their baby is extremely helpful. But I will leave to the Editors to decide whether they want to insist or not on the authors presenting such simple statistics to illustrate the frequency of codes and themes in the study (which I accept does not equate importance or prevalence in the population), and to support other statements. Otherwise the paper is a very useful addition to the literature, and I congratulate the authors for undertaking this study.

VERSION 2 – AUTHOR RESPONSE

We have considered the recommendation, and amended the text in two places (marked in red).