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The need for evidence: Response to letters relating to Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey. BMJ Open 2016; 6(8):e010996

Maggie Redshaw

Published on: 21 November 2016

Do not deny parents choice when their baby dies

Clea Harmer

Published on: 20 October 2016

http://bmjopen.bmj.com/content/6/8/e010996.responses#re-impact-of-holding-the-baby-following-stillbirth-on-maternal-mental-health-and-well-being-findings-from-a-national-survey-bmj-open-201668e010996

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Re: Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey. BMJ Open 2016;6(8):e010996.

Katherine J. Gold

Published on: 26 September 2016

Published on: 21 November 2016

## The need for evidence: Response to letters relating to Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey. BMJ Open 2016; 6(8):e010996

Maggie Redshaw, Associate Professor

Other Contributors:

Julie Hennegan, Jane Henderson

Dear Editor,

The topic of contact with the baby after stillbirth is a controversial subject about which feelings run deep. It is important to keep an open mind and allow the evidence to be heard. We discussed the limitations of this work within the paper, and would note that this study has similar, and in some cases fewer, limitations than previous quantitative work on this topic (Hennegan, Henderson & Redshaw, 2015). This paper does not recommend that parents be denied choice after stillbirth, and we agree that parents need support to make decisions that suit them and that these choices should be respected. We also believe that parents have a right to make informed choices about their care. Whilst parents should always be offered the opportunity to have contact with their baby, it should not in any way be forced upon them, even in the form of extra encouragement.

Gold et al suggest that women who declined to hold their baby may be fundamentally different at baseline from women who did hold their baby. Table 2 in the paper shows that there were few statistically significant differences on sociodemographic, clinical and care characteristics between the two groups. Differences in ethnicity, use of fertility treatment and multiple pregnancy were adjusted for in the analyses. Furthermore, the rates of long-term mental health conditions were very similar between the two groups.

This study is one of the largest of this type and one of the few to use random population-based sampling avoiding the biases associated with individual site or online-based responses. Studies of other research topics have also found that quantitative and qualitative findings diverge, such as debriefing following caesarean section (Small et al 2000; Murphy et al 2003; Kershaw et al 2005). We would note that the qualitative studies focus on outcomes such as satisfaction and reflections on the experience, not subsequent mental health and wellbeing outcomes which have been the focus of this quantitative research.

The findings of this study support the need for further work to clarify the ways in which contact with a stillborn baby affect parents in the short and longer term. More broadly, they endorse the argument for a longer term care pathway that supports parents who have experienced stillbirth.

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#### Conflict of Interest:

None declared

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None declared.

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#### Do not deny parents choice when their baby dies

Clea Harmer, Chief Executive

Dear Editor

http://bmjopen.bmj.com/content/6/8/e010996.responses#re-impact-of-holding-the-baby-following-stillbirth-on-maternal-mental-health-and-well-being-findings-from-a-national-survey-bmj-open-201668e010996

4/11/2018

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It is vital that the findings from a recent article published by Redshaw et al are not misinterpreted as evidence that parents should be denied choice after their baby has died. The study reports higher rates of mental health and relationship difficulties among women who held their stillborn baby compared with those who saw but did not hold their stillborn baby.

Sands supports the need for research to understand the impact of a baby's death on families, and we understand the parameters of the study in question. We are concerned, however, that some may suggest, based on these findings, that parents should not hold their dead baby. This would be a retrograde step.

Parents should always be offered the opportunity to see, hold and spend time with their baby. We know, from supporting thousands of parents, that many find great comfort in the memories they create at this time and the opportunity to make their baby a part of their family.

Not all parents will want to hold their baby. It's important that women and their partners should be supported to make the decision that feels most manageable for them in their circumstances, and that this choice is respected.

What's essential is that parents are given genuine choices and time to reflect and decide what they want. Parents should understand they can change their mind and options should be sensitively revisited if appropriate, without giving the impression of pressure.

The recently published 4th edition of Sands' Pregnancy loss and the death of a baby: guidelines for professionals provides clear guidelines on the principles of bereavement care. Sands also provides bereavement care training and many resources to support health professionals working in this area.

It is worth noting that the women and families in the study were recently bereaved, and therefore researchers were only able to ask them to self-report symptoms of anxiety and PTSD at 3 and 9 months after their baby had died. We know at Sands that the impact of the death of a baby lasts many years and changes over time.

Since Sands was founded by a group of bereaved parents in 1978, we have passionately supported parents having the choice over whether to see and hold their baby. We know many long-ago bereaved mothers who were not given this choice, and whose grief was compounded by not being able to not see or hold their own babies.

"I was never allowed to hold our son, only look at him in the incubator. We were not allowed to be with him when he was dying. No photographs taken. Things were very different in 1975." (Patricia Robertson, Argyll and Bute)

"The midwife gently asked me, would you like to see, maybe even hold your baby? My initial reaction was, NO! See, hold a dead thing? NO! But, the midwife knew it could be beneficial for me to see and hold my baby, because she had read the guidance on it in the first edition of the Sands guidelines, and so she asked again. And I did hold my baby and it is the best thing I have ever done in my life. I can remember her weight

in my arms, her fat cheeks, her rosebud mouth, her soft hair and I can remember thinking, this is my daughter not something to be afraid of, someone to be proud of." (Steven Guy, Northern Ireland)

What this study importantly highlights is that the death of a baby is a complex and traumatic experience for parents. Given how many women reported poor well-being in the months after their baby's death, their support needs are clearly not being met by current NHS services at what is a very difficult time.

Much more needs to be done in terms of supporting parents both physically and psychologically in the months after the death of their baby. Bereavement and follow up care cannot change the feeling of loss parents may feel, but poor care can compound it.

Clea Harmer, Chief Executive, Sands, www.uk-sands.org

#### Conflict of Interest:

None declared

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### Re: Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey. BMJ Open 2016;6(8):e010996.

Katherine J. Gold, Katherine J. Gold, Physician

Other Contributors:

Claire Storey; Dimitrios Siassakos; Susannah Leisher; Frances M. Boyle; Lynn Farrales; Alexander Heazell; Dell Horey; Jillian Cassidy; Margaret Murphy; Samantha Murphy; Joanne Cacciatore; and Vicki Flenady

Dear Editor: We were interested in the recent article by Redshaw et al. which reported higher rates of mental health and relationship difficulties among women who held their stillborn baby. 1 We agree this is an important topic, but after reviewing the article in depth, we would like to raise several concerns.

http://bmjopen.bmj.com/content/6/8/e010996.responses#re-impact-of-holding-the-baby-following-stillbirth-on-maternal-mental-health-and-well-being-findings-from-a-national-survey-bmj-open-201668e010996

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Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey | BMJ Open

(1) We note that this was a retrospective survey with a 30.2% response rate in which just 3% of women did not see and 16% did not hold their baby; these limitations were acknowledged but we believe they also restrict the ability to draw broad conclusions. (2) There was little exploration into the reasons why women did not hold their babies and if they had any regrets about their decisions. While four out of five women reported they did not hold because they could not or did not want to, the study did not account for the fact that women who declined may be fundamentally different at baseline, so that mental health outcomes may be due to underlying differences in mothers rather than their choices or experiences at birth. (3) While the authors emphasize that holding was associated with a trend toward worse mental health outcomes, their actual multivariable analyses show that at 9 months, the only statistically significant difference was higher odds of anxiety. Pre-existing anxiety could contribute to a woman's hesitance to hold the baby after delivery and separately serves as a predictor of postpartum mental health. (4) Even though there are many validated, widely-tested measures to assess postpartum depression, 2-5 anxiety, 6 and PTSD, 7, 8 in both live birth and bereaved mothers, this study used non-validated self-report measures which leads to the need for very cautious interpretation of the results. (5) The factors which have been demonstrated to be strong predictors of postpartum depression and PTSD include prior mental health conditions, interpersonal violence, and lack of social support.9-12 This study did not measure or control for any of these factors. (6) Another issue not addressed in this article is the well-acknowledged preference by parents to be given the option to see or hold their baby and strong evidence that the majority of women are satisfied with their decision.10, 13 Events surrounding the birth of a stillborn baby can have lasting impact on how a mother experiences, remembers, and copes with this event.14 The decision to see or hold a stillborn baby warrants additional investigation, but research must adjust for the known confounders which have been shown to predict development of mental health problems. Moreover, there should be recognition that the experience of a mother at the time of delivery is complex, and multiple pre-existing and intrapartum factors may affect subsequent outcomes and grief.

In summary, we believe it is not possible to reach a conclusion from this study about whether the decision to see or hold a stillborn baby is detrimental or helpful to be reaved parents and urge research to gain a more nuanced understanding of the factors which contribute to parental experiences at the time of delivery and which may influence long-term mental health outcomes. We strongly urge health care providers to continue to offer women the option to hold their stillborn baby, and to make this offer in a respectful, supportive, and normative manner.

No author has any conflicts of interest to declare.

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