

Parents need to be listened to after loss of baby to improve care

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Credit: AI-generated image (disclaimer)

An independent study giving a national picture of the NHS care experienced by parents of babies who died before or during birth, or as newborns, has been undertaken by Oxford University researchers, working in conjunction with the charities Sands and Bliss.



The study found that the quality of care provided, in these difficult circumstances, was generally good for the majority of couples.

However, there was variability in the quality of care. Some women experienced poor care, which was not sensitive to their concerns and needs, and in some cases the hospital's facilities could have been better equipped for them and their families.

Understanding parents' experiences is crucial for <u>health professionals</u> and policy makers to understand how maternity services can be improved, the researchers say.

The research in the National Perinatal Epidemiology Unit at Oxford University was funded by the Policy Research Programme of the Department of Health. The report 'Listening to parents: after stillbirth or the death of their baby after birth' is published today at a meeting at the Royal Society of Medicine.

Questionnaires were sent to women in England who had a stillborn baby or a baby who died as a newborn in two three-month periods in 2012. There were separate questionnaires for women whose baby was stillborn and for those whose baby died shortly after birth, and 473 and 248 women responded respectively. That represented a 30% response rate.

The surveys covered the care the women and their partners received during pregnancy, labour and birth, around the time their baby died and afterwards.

The responses showed the aspects of care from midwives and doctors that were most valued, say the researchers. Parents wanted to be treated with kindness and respect as individuals, and to feel that their needs were understood. They wanted their baby to be recognised as an individual, cared for and treated with respect. And most of all, they



wanted their worries and concerns to be listened to.

The survey responses showed that generally the majority of women felt they'd received good care and had been treated with kindness. However, at each point from pregnancy through labour and birth, a significant proportion of women and their partners felt their worries hadn't been listened to, they hadn't been taken seriously or they hadn't been wholly involved in treatment decisions.

While almost all women were given a private or single room after the stillbirth or death of their baby, in up to half of cases this was within earshot of healthy, crying <u>babies</u>.

The provision of follow-up care after leaving the hospital was particularly variable. Counselling and support was not always available for those who wanted it. The researchers say the survey responses show that more structured follow-up care and psychological support needs to be in place so that parents who want this can take it up.

The role of bereavement midwives was seen as very important. They were often singled out for special praise by parents completing the survey.

Lead author Dr Maggie Redshaw of Oxford University's National Perinatal Epidemiology Unit said: 'The death of a baby has a huge impact. And the quality of the care parents receive during this period, the kindness and respect they are shown, can have profound effects. Everybody – doctors, nurses, all staff – has the potential to make a difference to each individual woman and her partner going through this experience.

'The NHS is doing many positive things. There are families that say, "We were looked after in the best possible way when the very worst had



happened".

'But there are others who have described care which is not good enough and we know that this can be devastating for parents who are already suffering. We can't say from our survey whether this is about some units doing particularly badly or individual staff struggling in difficult circumstances, but we do know what is needed, and it is all there in the best examples of care. This needs to be implemented across the board.

'We hope that NHS trusts and individual members of staff will look at their services and their practice in the context of our report and the guidance which already exists, and take steps to improve the care they provide for women and their families affected by the death of a baby.'

Neal Long, Chief Executive of Sands, says: 'The value of this survey is that it identifies best practice, and the huge difference it can make to <u>women</u> and their partners at this most terrible time. But it also shows that access to high-quality support and facilities remains a bit of a lottery.'

Bliss Chief Executive Andy Cole said: 'This invaluable report highlights the often overlooked needs of all family members after the devastating loss of a baby. The report demonstrates that most healthcare professionals do an outstanding job in these extremely challenging situations, but best practice needs to be applied consistently across England to ensure that every single parent receives the vital care and support they need. There is a clear need for improved access to counselling to help families through such a tragic period of their lives and this is something that Bliss is committed to help achieve.'

More information: <u>www.npeu.ox.ac.uk/research/lis</u> ... h-neonatal-<u>death-248</u>



Provided by Oxford University

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