Paediatrics

Breaking bad news to parents about their child's prognosis

Parents of children facing terminal or life-threatening illnesses require timely information about their child's prognosis from healthcare professionals and an opportunity to provide input into the discussion, a qualitative study from the Netherlands has found.

The researchers carried out a comparative analysis of in-depth face to face interviews with 64 parents of children, aged 1-12 years, who had suffered, or died from, a life-threatening or terminal condition.

The interviews were carried out between 2016 and 2018, mainly in the parents' homes, and lasted 2 hours on average.

The aim was to analyse parents' experiences of both barriers and facilitators in communication of bad news about their child's condition.

Interviews were recorded and transcribed verbatim and then evaluated.

The researchers identified ten key themes to the communication of bad news from the interviews.

A lack of timely communication
During the child's treatment, some parents seemed to be unaware that their child might not survive. There was little or no discussion about the fact that their child might die.

Failure to ask parents for input
Parents appreciated conversations in which they were treated as equals. They wanted doctors to take them seriously when they flagged up symptoms or evaluated their child's quality of life.

Parents feel unprepared during and after the conversation
Parents often felt overwhelmed by the conversation because they were not sufficiently prepared beforehand. Participants also reported being unable to find a quiet space to absorb the bad news and decide what to do next.

A lack of clarity about future treatment
Some, but not all, parents felt that having been informed that their child's illness was incurable, they were not told what to expect in terms of care and support.

Doctors' failure to voice uncertainties
Honesty about doctors' lack of certainty was appreciated. Parents did not mind uncertainty as long as this resulted in honest conversations, and that conversations should not be delayed until more certainty was possible.

Failure to schedule follow-up conversations
Parents found it difficult to assimilate the bad news and ask appropriate questions straightaway and would have appreciated a follow-up interview to ask questions.

The presence of too many or unknown healthcare professionals
Sometimes when bad news was conveyed a whole medical team, many of whom were unknown to the parents, would be present whereas parents were only familiar with the consultant and would have preferred a one to one conversation.

Parental concerns about how bad news should be broken to their child
Most of the parents were positive about the way in which bad news had been broken to their child. However, some parents disagreed with doctors about how much their child should be told about their illness. Other parents felt abandoned when it came to discussing illness and death with their young child.

Managing indications of bad news in non-conversational contexts
During the treatment period, sometimes important information was inadvertently conveyed by indirect means i.e. notes on a hospital bed, an investigation suddenly brought forward or overheard conversations. Parents wanted openness so that information was given in a planned way.

Parents' misunderstanding of medical terminology
Parents did not always understand, or misinterpreted, the medical terminology used by doctors.

The study authors state: 'When parents voice dissatisfaction about their children's care, this tends to be about communication, rather than the purely medical aspects of care.

'By studying the ways in which parents perceive communication of bad news, we can learn how to improve the way in which we communicate when caring for children with life-threatening conditions.

'Above all, we need to remind ourselves to talk to parents about the future of their child, especially when the prognosis is uncertain.'

These findings are a useful reminder to all healthcare professionals about the key points we need to consider when breaking bad news to parents about a life-threatening or terminal condition in their child.

It is important to appreciate that the parents' understanding of medical terminology may not be the same as ours, a good reason to clarify their understanding at the end of the discussion.

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Brouwer MA, Maeckelberghe ELM, van der Heide A et al. Breaking bad news: what parents would like you to know. *Arch Dis Child* 2021;106:276-81

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