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BRIEF REPORT

No impact of previous evidence advocating openness to talk to children about their imminent death

Communication is as important as the drug and the knife in medical care, particularly when patients are facing life-threatening conditions. However, the ability to communicate effectively has been commonly associated with strong emotional barriers among healthcare professionals and family members. Studies that have focused on paediatric oncology have showed that openness about the transition from curative to palliative care is frequently avoided.[1,2] As long ago as the 1980s, a paper in this journal reported that children often wanted to share their thoughts and feelings at the end of life, but that adults often failed to recognise that need.[3]

In 2001, we conducted a national Swedish questionnaire study on factors in care that can be avoided or modified to mitigate the risk of psychological morbidity in bereaved parents.[4] We surveyed the parents, who were identified from national registers, 4–9 years after their children had died of malignancies. One finding concerned their readiness to talk about imminent death with their seriously ill child. It emerged that just over one-third of the 429 who answered that question had talked to their children about death and none of the parents regretted doing that. However, more than a quarter of the parents who did not talk to their children later regretted that and that lack of communication was associated with a high risk of psychological morbidity. This suggests that healthcare professionals could encourage families to talk with their child about imminent death, in particular when the child is aware of the inevitable.[4]

In 2016, we conducted another nationwide questionnaire study of parental psychological health after they lost a child to a malignancy 1–5 years earlier, in 2010–2015.[5] The study was approved by the Swedish National Ethical Review Agency and 220 parents answered the question about discussing death with their child. By combining the results of the new study and the previous study, the risk of psychological morbidity over a period of up to nine years after bereavement could be assessed. Swedish National Registries were used to identify the children and the parents, as they were in 2001. The children had been diagnosed with a malignancy before the age of 16 years and died before their 25th birthday due to the illness. The 15-year gap between the completion of the 2001 and 2016 studies enabled us to assess the potential changes in attitudes to prognostic openness. We wanted to know whether communication with the sick child about imminent death had become more widely adopted in paediatric oncology over the 15 years between the two studies. To address this issue the responses to three questions that were raised in both 2001 and 2016 were analysed. We asked the parents if they had talked about death with their child. If they said yes we asked them if they had regretted doing that. If they said no we asked them if they regretted not speaking to them.

As can be seen in the Table 1, the results were almost identical, apart from the difference in the response rate: in 2001, it was 80% and in 2016, it was 43%. The lower response rate in 2016 may be partly attributed to the inclusion of parents born outside the Nordic countries with limited understanding of Swedish, who were excluded from the 2001 study. Moreover, it may be due to the 2016 study containing quite a number of more elaborate psychometric scales than the 2001 study.

The most striking, if not disappointing, finding of this study is that no change had occurred over time in terms of prognostic openness with the child and regrets among parents of children at imminent risk of death from a malignancy. Presumably, this was due to emotional barriers and, or, healthcare staff receiving insufficient training in communication.[2] The main finding of unchanged attitude to prognostic openness is concerning. However, it should be noted that most of the parents had not talked with their child about death, nor did they later regret this. Hence, prognostic openness cannot be generally recommended. Instead, every child and parent should be acknowledged as individuals and communication should be tailored accordingly. Most importantly, staff should be responsive to the child's awareness of imminent death. Not all children have the capability of expressing themselves verbally, which could depend on age, symptom burden or simply reluctance to share the inevitable. Some children display their awareness in drawings, play and what movies they preferred to watch. Culture and faith may also play a role in the child's and families' willingness to openly communicate about death. Nonetheless, we are convinced that the number of parents that have regrets during bereavement can be reduced by sensitive communication throughout the illness trajectory.

A strength of this report was the nationwide sample. It may be argued that time after bereavement might impact the accuracy of responses, but the results were almost identical regardless of the time that had elapsed after the bereavement. Further prospective studies may offer information about the best approach when communicating with seriously ill children about the possibility of their imminent

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TABLE 1 Comparison between whether parents talked to their child about death in 2001 and 2016 and whether they regretted that conversation or lack of conversation

	Parent talked to child	Regretted talking to them	Parent did not talk to child	Regretted not talking to them
2001 cohort n = 429 (80% response rate)	147 34%	0 0%	282[a] 66%	69 27%[a]
2016 cohort n = 220 (43% response rate)	68 31%	1/68 1.5%	152 69%	36 24%

[a]Only 258 out of the 282 parents responded to the specific question about regrets (69/258 = 27%).

death. This would not only help the child, but may also reduce the risk of psychological morbidity in the bereaved parents.

CONFLICT OF INTEREST

The authors have no conflicts of interested to declare.

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