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CHILD AND FAMILY WISHES: A CASE NOTES REVIEW OF END OF LIFE CARE PLANNING FOR CHILDREN WITH LIFE-LIMITING CONDITIONS

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Aim To assess compliance with ACT standards (ACT 2004) in respect of end of life (EOL) planning for children who died from life-limiting conditions between October 2008 and March 2010 (defined geographical area).

Methods Retrospective case note review. A standardised data collection tool was used and eligible children were identified from Child Death Overview Panel data.

Results 42 sets of National Health Service notes were reviewed, relating to 20 children. The notes of 75% children contained EOL 'care plans'. In most cases, these child and family choices were found buried among the narrative of the case notes. Discussions about what to do in the case of acute life-threatening event were common (75%). Discussions about wishes during life (25%) and wishes after death (25%) were rare. In 50% cases location of death was either not discussed or no location other than hospital was considered. There were several areas of good practice. Timely and comprehensive discussions were particularly likely where staff had training or expertise in palliative care. Factors causing EOL discussions to be avoided or delayed were diagnostic or prognostic uncertainty, outstanding investigations or any element of ongoing curative management.

Conclusions The ACT standards in relation to EOL planning are being met to varying degrees and specific areas for development are identified. A locally developed tool exists for facilitating the discussion and documentation of child and families' choices with regard to EOL. Clearly defined indications about when to consider using this tool and how to ensure that the information it gathers is effectively disseminated, will be crucial to its successful implementation. Funding has been secured to provide training in the use of this tool.



Child and family wishes: a case notes review of end of life care planning for children with life-limiting conditions

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