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Patient Education and Counseling

Volume 62, Issue 2, August 2006, Pages 228-234

Parents' information needs about the treatment of their chronically ill child: A qualitative study

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<https://doi.org/10.1016/j.pec.2005.07.006>

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Abstract

Effective information provision is a prerequisite for partnership between child patients, their parents and health professionals.

Objectives

To explore the complexity of parents' information needs and how current information provision is evaluated.

Methods

Qualitative methodology using semi-structured interviews with 27 parents of 20 families with a chronically ill child, recruited at the paediatric department of a British district general hospital.

Results

The need for information varied greatly between individuals and over time, and commonly involved diagnosis, management plan and prognosis. However, most parents in this study experienced professional communication and information provision to be inadequate. Information provision appeared to be related to the diagnosis, the level of secondary care involvement and the extent to which parents were required to take responsibility for daily management of the child's condition. Parents' complex and shifting evaluations and responses point to the double-edged nature of information. Some parents actively sought out information, but resisting information, for fear of its potentially negative impact, was also noted to be a coping strategy.

Conclusion

Parents of chronically ill children presented with a great variety of information needs, which was not always appreciated by healthcare professionals.

Practice implications

This study highlights the need for good communication based on professional awareness of how parents understand and experience their child's illness, as well as the importance of sensitively individualising information provision to parents' needs so as to address their requirements but not to unnecessarily increase their anxiety or insecurity.



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Keywords

Parents; Children; Chronic illness; Information needs

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