Decision-making around gastrostomy-feeding in children with neurologic disabilities

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CRD summary
The objective was to explore the decision-making experiences of parents of children with a neurologic disability, in relation to gastrostomy tube feeding. The authors concluded that decisions were shaped by the values associated with feeding methods, child and family context, and the process of decision making. The conclusions reflect the evidence presented and the recommendations for research seem justified.

Authors' objectives
To understand the decision-making experiences, perspectives, and beliefs of parents of children with a neurologic disability, in relation to gastrostomy tube feeding.

Searching
MEDLINE, EMBASE, PsycINFO, CINAHL, and Sociofile were searched up to July 2010, for English-language studies. It appears that only published articles were sought. Some search terms were reported. The search strategy was developed by an experienced librarian. Additional searches were carried out of reference lists, by citation tracking, and in personal files.

Study selection
Eligible for inclusion were qualitative studies (using in-depth interviews or focus groups) exploring the experiences of parents of children (aged 18 years or younger), where at least half of the children had a neurologic disability and were tube-fed or tube feeding was being considered. Studies had to report data relating to decision-making for the intervention. Observational epidemiologic studies and surveys were excluded.

The included studies were conducted in the UK, USA, Canada, or Australia, and published between 1995 and 2008. Decision-making was the primary focus in just under half of the studies. Where reported, the age of the children ranged from two weeks to 19 years. In addition to the experiences of parents, the review assessed the experiences of health care professionals, including paediatricians, nurses, allied health professionals, surgeons, dieticians, and teachers. Most studies collected data after gastrostomy.

Two reviewers selected the studies for inclusion. Disagreements were resolved by consensus with a third reviewer.

Assessment of study quality
The quality of reporting was assessed by the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist, covering the research team and reflexivity (involvement in the study), study design, data analysis and reporting.

It was unclear how many reviewers assessed quality.

Data extraction
Two reviewers extracted the data. Disagreements were resolved by consensus with a third reviewer.

Methods of synthesis
A thematic synthesis was carried out by two reviewers. This included line-by-line coding of the text of each study to develop relationships and concepts. Key concepts were identified, and participant quotes were extracted to illuminate these concepts. Descriptive and analytic themes were developed with specific reference to the review question. An illustrative conceptual model was presented.

Results of the review
Eleven qualitative studies (range seven to 50 participants) were included in the review. The quality of reporting was variable (COREQ scores ranged from 13 to 26 out of 32). All studies reported the sample size and described their participants; and all provided participant quotes in the results. Fewer than half the studies reported their methodologic
or theoretical approach; three quarters of them provided interview questions or guides; and only two carried out participant engagement to validate their results.

Decisional conflict was the overarching characteristic. This was explained by three main themes: values, context, and process.

**Values:** Values were dominated by difficulties experienced by parents in rationalising the benefits beyond achieving adequate nutrition of feeding by mouth, and the conflict this presented in the loss of these benefits due to gastrostomy tube feeding. There was divergence between the views of parents and health care professionals on the importance of weight gain.

**Context:** The different contexts in which decisions were made (the unique child, parent, and family characteristics) were seen as important moderating factors to decision making. These included, for example, parental understanding of the diagnosis, views about physical health, and previous experiences of disabilities and life expectancy of the child. The level and nature of family support, family culture, and decision-making style preferences were also relevant.

**Process:** The process of information sharing and support from different health care professionals was influential in decision making. Specific issues were highlighted, such as inadequate information and support, conflicting information, and inappropriate timing of information in relation to gastrostomy feeding. Health professionals noted the lack of evidence on the effectiveness of tube feeding, and the difficulty this presented for decision making.

Further results, supported by participant quotes, were reported in the review.

**Authors’ conclusions**
The values associated with gastrostomy feeding and feeding by mouth, the context of the child and family, and the process of decision making, facilitated by the health care system, shape parental experiences and decisional conflict.

**CRD commentary**
The review question was clear and the context was presented. The inclusion criteria were sufficiently detailed, but the inclusion of views from health care professionals appears to conflict with the participant selection criteria (as reported). The search included several relevant databases, and the process was aided by an experienced librarian. Language restriction can be beneficial for qualitative research, but possible publication bias means that studies may have been overlooked.

The review process was generally well reported, and the results were presented with a clear audit trail supported by participant quotations. The authors considered inconsistent data (received from parents who did not experience decisional conflict). The quality of reporting in the included studies was variable, with participant validation of the results being notably scarce. The authors drew attention to the limitations of their review, including limited transferability to other family contexts, and the variable timing of data collection in the included studies.

The authors’ conclusions reflect the evidence presented and their particular recommendations for research seem justified.

**Implications of the review for practice and research**

**Practice:** The authors stated that the results of this review will help guide interventions, such as aids to improve parental decision making. Specific recommendations for clinicians included not focusing solely on the physical health of the child, clarifying fears and expectations about gastrostomy feeding, offering practical strategies for families, and allowing adequate time for decision making.

**Research:** The authors stated that further research (qualitative and quantitative) was needed to understand decisional conflict and best practice for gastrostomy feeding. Studies should focus on decision making, include a wide variety of parental contexts and views of experienced clinicians, and have standardised data collection.

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