This systematic review explored the impact of gastrostomy tube feeding on families and children with complex needs, after a tube has been inserted.

The review included 13 studies. The inclusion criteria required that studies were qualitative, focussing on children with neurological impairment predominately, and on the lived experience of gastrostomy tube feeding. The review process is clearly described. A thematic analysis determined three over-arching themes; the child, the parents and the family. Child impacts concerned physical outcomes, quality of life, and socialisation. Parents experienced changes in caregiving and stress, parent-child relationship, parent-medical system relationships and stigma. Family themes were context specific e.g. financial implications.

There were positive and negative impacts of tube feeding for children, parents and families. It is important to note that the same impact e.g. weight gain, was viewed both positively and negatively in different families. These themes can be useful in providing information to families and children while deciding about tube placement, and to support ongoing if/when a tube is placed. The reviewers suggest use of these themes in discussions with families and recommend the development of a formal ‘decision aid’.


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