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REVIEW

Psychosocial aspects of feeding children with neurodisability

GM Craig

The psychosocial support needs of parents considering a gastrostomy feeding tube for their disabled child are often overlooked, yet there is a growing body of evidence that attests to the decisional conflicts parents, often mothers, experience. This may be in addition to the stress associated with feeding a disabled child. The support needs of families and caregivers should be assessed, including the values parents attach to oral and tube feeding. Structured support should be embedded within the care pathway and both professionals, and service users, with appropriate training should be identified to ensure parental information needs, and any emotional, practical and financial issues are addressed.

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INTRODUCTION

A high proportion of children with neurodisability, such as those with severe cerebral palsy (CP), experience disorders of swallowing and feeding with implications for their nutrition, growth and overall health.[1] Dysphagia, although often under-recognized in this population of children[2] is common, with reported prevalences ranging from about one-fifth of children with CP of any degree,[3] to 99% in children with severe CP and intellectual disability.[4] Pulmonary aspiration is also common (where food or fluid enters the airway).[5] Caregivers, usually mothers, report prolonged mealtimes, which can be experienced as stressful.[6] In some cases, caregivers spend in excess of three hours per day feeding with individual mealtimes lasting more than half an hour.[6]

Not surprisingly, mothers may feel that their everyday lives are dominated by feeding, particularly where a child refuses to feed from anyone else, which can be experienced as isolating, as mothers feel unable to leave their child, go out to work or socialize. The demands of care can be high in this population of children as they are frequently ill and require numerous visits to health professionals and periods of hospitalization.[7] Frequent hospital appointments, because of the complexity of children's needs, and the lack of integrated services, in some cases, can also create additional demands on children and their caregivers, pointing to the importance of the role of key workers in coordinating children's care.[8]

Research into the benefits of gastrostomy tube feeding reports improvements in health and weight gain[7,9] and decreased stress, as experienced by caregivers.[10,11] Parents also report a reduction in the amount of time spent feeding and ease of administering medication and liquids (by tube rather than orally). They generally worry less about their child's nutrition with the knowledge that they are getting sufficient via the tube.[12] Despite the benefits, the suggestion of a gastrostomy feeding tube (GFT) can generate opposition for some families.[13,14] For others, however, an alternative to feeding by mouth may come as a welcome relief. Occasionally, families may find their request for a gastrostomy tube is met with the advice to 'persevere' or 'try harder' from clinicians, as guidelines on the use of gastrostomy are underdeveloped. Research across six European countries, for example, has demonstrated considerable variation in the use of GFT and the age at which they are placed, which could be attributed, in part, to variations in clinical practice.[15] Delaying surgery may add to the stress already experienced by caregivers. Ongoing assessment of parental psychosocial support needs and their ability to cope with oral/nasogastric tube feeding, with a view to moving toward feeding by a GFT, should form an essential aspect of clinical care.[16,17]

SUPPORTING PARENTS THROUGH THE DECISION-MAKING PROCESS

There is a growing body of literature, which highlights those factors influencing parental decision making in relation to the placement of a gastrostomy. This research emphasizes the importance of understanding the symbolic meanings of GFTs in relation to maternal identity, the maternal role, food, feeding, eating and child development.[17–22]

FEEDING AND THE MOTHERING ROLE

The suggestion of a GFT may challenge the 'good mother narrative' and signify maternal failure. Mothers may blame themselves for the child's inability to feed and poor growth or feel blamed by members of the extended family. Whereas a 'fat' baby is often a sign of good health in some cultures,[23] a thin child may be associated with a neglectful and poor mother. This may have a particular resonance in cultures with a history of deprivation.[24] Although parents may feel anxious about a child having an operation, the decision to elect for a GFT can be viewed as distinctive because feeding children as well as their growth and development are often deemed to be the responsibility of mothers.[22]

Caregivers may find feeding stressful but this does not always indicate their readiness to accept a GFT. Feeding may be described as 'difficult' or 'slow' or even akin to a 'war' or 'battle'[17] reflecting the difficulties around feeding. However, some mothers also designate mealtimes as a 'special time' and a time for intimacy and closeness,[17] which they fear they will lose if their children were fed by tube only. Tube feeding can signify many things and it is important to explore what parents feel they are 'giving up' versus what they are gaining, when they agree

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to feeding by tube. Listening to parental narratives and the meanings they attach to feeding can provide important information on how best to offer support. For example, advice that 'special time' with children can be simulated through other activities including bathing, play and preparing for bedtime may assist mothers to reframe 'good mothering' and enjoy 'special time' with their children in ways other than through feeding.

INVESTMENTS IN ORAL FEEDING: DISABILITY AND CHILD DEVELOPMENT

There may be many reasons for parental investment in oral feeding, not least because of the assumed pleasure children derive from eating and the experience with different tastes. Underpinning parental desire for children to experience different types of food is the belief that eating orally is important for language acquisition or has developmental benefit.[17] Children's ability to manage different textures may also be taken as evidence of their progress in achieving developmental milestones. A return to 'liquid food' with little opportunity to experiment with tastes and textures or for children to indicate their preference may be viewed as a regressive step in terms of children's development.[25]

Other compensatory experiences can be encouraged such as massage, kissing and touching while children are tube fed. Advice on mouthing toys, suitable for children's age and needs, which simulate mouthing experiences, can also be discussed with a speech and language therapist.[26]

The importance of the family meal and eating together is often mentioned by parents as a barrier to tube feeding, especially where mealtimes are seen as a time for conversation, inclusion and participation. Parents may need advice on how to manage tube feeding in the context of the family meal. For example, feeding the child at the table and encouraging play with feeding utensils.[16]

For some families, the suggestion of a gastrostomy may be received negatively, a new diagnosis that they have to come to terms with.[17,27] It may signify permanence and hence further evidence of a child's disability. This may be challenging for parents coming to terms with a child's disability and trying to normalize family life.[28] Some parents may deny that their child has a feeding difficulty altogether. In these cases, input from a psychologist, to discuss age appropriate feeding and offer emotional support, may assist parents to come to terms with the idea of feeding their child by tube in the future.

The suggestion of a GFT may be more acceptable to those families where children are already fed by a nasogastric tube, particularly in cases where a child has had a tube since birth. For these families, tube feeding may be seen as a natural progression or the next step. Although a nasogastric tube is only intended as a short-term solution, children may have been fed by nasogastric tube for many years, which is not ideal, and can place demands on both caregivers and children. Parents would benefit early on from a care plan with goals for children's feeding identified in the short, medium and long term with dates for review.

Parents are often anxious that their child will refuse to eat orally following surgery for a GFT, as some children begin to stop eating by mouth for reasons that are not entirely clear. In some cases, professionals may advise against oral feeding altogether because of the risk of pulmonary aspiration and the association with respiratory disease.[29] Although some experts currently question the necessity of a complete nil-by-mouth regimen for the majority of children with CP, other health care professionals may feel reluctant to take this risk.[30] On the other hand, parents may be reluctant to accept professional advice that oral feeding is unsafe.[30] This can be controversial particularly where aspiration is 'silent', with no obvious, outward sign of distress.[30] Advice to parents on the safety of oral feeding should be given within the context of the multidisciplinary team following appropriate investigations and assessment of risk.[26]

Although feeding by tube might make life easier for caregivers compared with oral feeding only, this may not be the best advice to give mothers who want to hear about the benefits to the child. It may help to stress some of the developmental benefits to children that parents report following gastrostomy insertion. For example, some parents notice that children are more alert and more able to concentrate and that there is more free time for parents to spend with siblings. Moreover, it is better to prepare families for some of the possible negative aspects of gastrostomy feeding as caregivers will have to learn new nursing procedures and there may be side-effects of surgery.[7]

Not all anxiety about tube feeding is psychological, however, and parents may have concerns about incurring additional costs associated with tube feeding and its affordability, particularly where equipment and feeds are not provided as part of a health plan or health service. Here, financial advice may be necessary.

DEALING WITH THE UNEXPECTED: PREPARING CHILDREN AND FAMILIES

Some families may only receive information about the practical side of managing tube feeding following surgery. However, research suggests that families would like the information sooner, including the impact of tube feeding on child and family in the context of their everyday lives.[17]

Information needs include: how to care for the tube; training carers to provide tube feeding in different contexts, such as school and residential care; how to explain tube feeding to siblings; practical tips for going on holiday abroad or short trips; and children's ability to engage in physical and therapeutic activities, such as swimming and physiotherapy.[17] Providing checklists of items for families to research in advance of surgery may also prove useful. For example, research has suggested that children may be excluded from school or short-term residential care because of a lack of trained staff to feed children by tube.[31] Families need to be prepared for these potential setbacks.

Parents might also express concerns that tube feeding is a form of 'force' feeding. They may be uncertain about whether to feed a child experiencing illness, particularly where loss of appetite is often the first sign. Parents can benefit from advice on how to manage these scenarios from other families or parental support organizations.

Appropriate post-operative care, both practical and emotional, is imperative. Families may experience problems obtaining the equipment or feeds and, in some cases, they can experience problems managing the equipment or caring for the stoma.[31] Families should be provided with information signposting them to the relevant services and key people to contact before discharge from hospital.

Finally, parents may experience additional stress because of their interactions with the clinical services (number and frequency of contacts) and the complexity of care pathways. Parents may feel disempowered as professionals seemingly take 'charge' of children's care leaving parents as 'silent partners'.[32] Clinicians may also use language that inadvertently reinforces blame and challenges mothers' parenting skills. Terms such as: 'failure to thrive' and 'malnourished' are best avoided. Actively involving parents as partners in decision making[33] and valuing their expertise as feeders and carers can assist parents to feel less de-skilled in clinical encounters.

To summarize, families can be supported by managing their expectations, involving them to identify goals that are important to them, recognizing their expertise, building in time to discuss psychosocial aspects within the clinical care pathway and putting families in contact with other parents with experience of tube feeding. Ensuring adequate information on all aspects of gastrostomy feeding including the practical, social and emotional aspects is essential.[31] (See Appendix for a list of supportive suggestions.)

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CONFLICT OF INTEREST

GM Craig has received payment from Nutricia Ltd for a lecture and travel expenses.

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APPENDIX

SUGGESTIONS FOR SUPPORTING FAMILIES*

Who should be involved?[26]

Parents
Child
Consultant pediatrician
Gastroenterologist/surgeon
Speech and language therapist
Dietician
Occupational therapist
Clinical nurse specialist
Psychologist
Key worker (coordinate complex care)
Advocate

PREPARING THE ENVIRONMENT FOR A DISCUSSION OF FEEDING

Discuss somewhere private without interruptions
Provide privacy for parents afterward
Ensure interpreters available where necessary (book in advance)

COMMUNICATING NEED FOR TUBE FEEDING

Introduce members of the multi-disciplinary team (MDT) and their roles
Provide clear information
Manner—honest, warm and sympathetic
Positive tone (avoid ‘I am afraid’, ‘unfortunately’)
Avoid language that communicates blame
Explore parental narratives and meanings they attach to tube and oral feeding including any investments in oral feeding
Avoid a sole focus on food and weight and ask about feeding and relationships[34]

INVOLVING PARENTS AND CHILDREN IN DECISION MAKING

Involve parents and child in all aspects of decision making
Involve children who may be able to communicate through a communication aid or discuss with parents how best to communicate with the child depending on age and severity of disability
Discuss a range of options for feeding with appropriate timelines for review
Explain the role and purpose of tests and investigations in informing decision making
Invite parents to ask questions throughout the appointment (not at the end)
Give parents time to think about questions (provide pauses)
Encourage parents to express their concerns
Acknowledge and value the expertise of parents in caring and feeding children
Explore other sources of stress the family may be experiencing, for example, family tensions, financial difficulties and other care-giving demands (responsibility for caring for other members of the family, or sick and disabled children)
Explore parental support mechanisms. Ask what assistance they feel they could benefit from. Build on existing strengths.

CONSOLIDATING (ADAPTED FROM BAIRD *ET AL.*[35] ON DISCLOSURE OF A DIAGNOSIS OF CP)

Give a summary of discussion and outcome in writing, including parental views
Use child-friendly aids to assist communication with children, for example, storybooks with pictures of children with a gastrostomy or a gastrostomy demonstration doll
Offer an introduction to another child, parent or support group
Offer another (flexible) appointment to discuss GTF
Offer to talk to other family members
Signpost to other information and resources on GTF and the surgical procedure, parents may want to see examples of different types of gastrostomy
Offer appointment with the clinical nurse specialist and/or psychologist

COORDINATING CARE

Identify named key worker
Integrated care pathways
Guidelines that link community and specialist services[17]

POST-SURGERY DISCHARGE PLANNING[16]

Ensure sufficient supervised practice in administering feeds
Ensure caregiver is confident in using and cleaning the equipment before discharge
Provide instruction on care for the stoma and whom to contact for advice
Give information on how to store feeds
Provide a named contact for coordinating supplies of equipment and feeds
Provide a named contact in the event of the tube becoming blocked or if parents experience difficulties with the equipment

FOLLOW-UP

Ensure appropriate clinical and dietetic input
Offer support in reinstating oral feeding where appropriate
Give advice on oral/dental hygiene
Offer psychosocial support

*Given that there are no guidelines on how best to support families considering a gastrostomy for their disabled child, a number of sources drawing on the wider literature have been used and adapted to inform these suggestions, which may be applicable to a wider range of children with feeding disabilities beyond the CP population.