Pros and cons of gastrostomy feeding in children with cerebral palsy

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Abstract

At least a third of children with moderate to severe cerebral palsy (CP) will have feeding difficulties. Malnutrition should not be considered normal in children with CP. Early, persistent, and severe feeding difficulties are a marker for subsequent poor growth and developmental outcomes. Growth patterns in children with cerebral palsy are associated with their overall health and social participation. Growth restriction increases progressively with age and thus mandates early nutritional intervention. In children with severe CP such nutritional intervention is increasingly being administered by gastrostomy feeding tube but controversy surrounds the evidence-base for this approach. Moreover, mothers' decisions about gastrostomy feeding are complex and difficult and must be taken into account in making therapeutic recommendations. This paper discusses the available research evidence and psychosocial issues around gastrostomy feeding in children with severe CP. It seeks to provide a basis for rational clinical decision-making based upon the integration of the best available research evidence with clinical experience and patient values.

Keywords cerebral palsy; decision-making; enteral feeding; gastrostomy; mothering; neurologic disability; nutritional status

In the mid-20th century text books on cerebral palsy (CP) in children made no reference to the feeding and nutritional problems that are common in this group of children. It is really only in the last twenty years or so that these have attracted research interest. Nevertheless, even now in some quarters the nutrition and growth deficits in children with severe CP are not recognized or deemed to be a low clinical priority. For the paediatrician, however, it is important to appreciate that neurological impairment — and its nutritional consequences — will remain important clinical problems in children.

Epidemiological data show that in those who are premature, weighing less than 1500 g at birth, CP occurs in up to 65 per 1000 live births. Although the survival of preterm neonates of 22–25 weeks gestation has improved from 1995 to 2006, the proportion (25%) with severe disability is unchanged. Many survivors of neonatal intensive care will grow up with a disability so profound that they are never likely to become independently mobile, to communicate effectively with others or to feed themselves. Moreover, against this background of an unchanged prevalence of disability, there is evidence that life-expectancy is increasing in people with CP with around half surviving into their late 20's.

Perhaps reflecting a better understanding of their nutritional requirements, many of those surviving have received gastrostomy feeding which has become much more widespread over the past two decades. At least a third of children with moderate to severe CP will have feeding difficulties and their consequences. The North American Growth and CP Project showed that for such children, feeding dysfunction is a common problem and that associated with poor health (more days ill in bed, hospitalization, missed school) and poor nutritional status (66% were stunted, and 44% had low fat stores). These growth deficits correlate with the severity of CP.

Causes of feeding problems

The relationship between oral-motor dysfunction and growth retardation is well recognized. Moreover, oral-motor function mirrors general motor function; swallowing difficulties have been reported in virtually all children with CP classified as Gross Motor Function Classification System (GMFCS) IV or V, the majority (76%) of which exhibit moderate to severe dysphagia. Oropharyngeal incoordination is associated with slow rates of feeding, extended feeding times, excessive spillage of food, and compromise to the safety of the swallow. Inefficient and slow feeding limits food intake and mothers spend protracted periods of time (up to 8 hours a day in some cases) attempting to feed their disabled child. While prolonged feeding may compensate for feeding inefficiency when the child is small, as body size increases a point is reached at which no further compensation is possible and growth is limited by energy intake. In addition to oropharyngeal incoordination other factors contribute to the feeding and nutritional problems in children with CP including, severe hand impairment, poor cognitive abilities, vomiting, poor dentition, early satiety, communication defects and behavioural disturbances. In passing, it is important to note that the problem is not confined to those with severe oral-motor dysfunction alone, even children with only mild feeding dysfunction, requiring chopped or mashed foods, also may be at risk for poor nutritional status.

The contribution of specific brain injury does not adequately explain growth faltering in children with neurodisability. Equally, undernutrition does not explain all of the growth failure, especially linear growth failure, in children with CP. It is likely that nutritional status accounts for only 10%–15% of the variability in linear growth of children with CP. Neurological disease itself may affect linear growth because linear growth failure correlates with the severity of cognitive defect and with ambulatory status. In children with hemiplegia, the affected side is usually shorter and smaller than the non-affected side, thus demonstrating the effect of the neurological disease on growth.

Consequences and management of undernutrition

The main consequence of undernutrition, therefore, is growth failure. Children with moderate or severe CP have poor growth compared with typical children and this correlates with markers of health and social participation; bigger children with CP have

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better health and more social participation than similar smaller children. Other consequences include decreased cerebral function which is associated with reduced potential for development, reduced responsiveness and noticeable withdrawal and irritability. Corollaries of undernutrition include: impaired immune function which increases the risk of infection, reduced circulation time which increases the risk of poor healing and pressure sores, and diminished respiratory muscle strength which is associated with weak cough and more chest infections. As argued above, the number of these children is unlikely to decline and their life-expectancy will increase, thus attention to their nutritional status is an indispensable part of the overall management of their health.

The principles of nutritional assessment and management are described in detail elsewhere (see reading list). Enteral tube feeding is frequently indicated in children with CP with significant oropharyngeal incoordination who are unable to meet their nutritional requirements orally.

Nasogastric tube (NGT) feeding is most often used for short-term enteral tube feeding — often prior to insertion of gastrostomy tube. There are several limitations for long-term NGT use including: nasal discomfort, irritation or penetration of the larynx, oesophageal erosion, recurrent pulmonary aspiration, blockage or displacement of the tube. Weight gain in children followed for over a year is better in those with a gastrostomy compared with those with an NGT. Furthermore, survival rates among children with severe neurological disabilities fed by gastrostomy tube are significantly better than those fed by nasogastric tube.

This paper deals with the advantages and disadvantages of gastrostomy tube feeding for children with moderate to severe CP.

Indications for gastrostomy tube feeding

The range of indications for insertion of a gastrostomy feeding tube in paediatrics is extensive but, in fact, the commonest indication for gastrostomy insertion is to overcome oral-motor impairment and feeding difficulties in children with neurological impairment and predominately those with CP. Insertion of a gastrostomy feeding tube is an increasingly common intervention in neurologically impaired children who: have a clinically unsafe swallow; are unable to maintain a satisfactory nutritional state by oral feeding alone; have an inordinately long (>3 hours/days) oral feeding time; are dependent on nasogastric tube feeding.

Methods of insertion

For much of the 20th century the Stamm gastrostomy, which requires surgical laparotomy, was the most commonly accepted insertion technique. The Percutaneous Endoscopic Gastrostomy (PEG) technique introduced in the 1980's has the advantage that it is minimally invasive, can be performed by a gastroenterologist, is relatively inexpensive and, if the patient's condition precludes use of a general anaesthetic, it can be performed under sedation. To prevent the complication of local or systemic infection, the prophylactic use of antibiotics with the insertion of PEG is recommended. PEG tube insertion can be performed as a day case, preferably under general anaesthesia, and takes less than ten minutes. Nevertheless, children are often admitted to hospital for a period postoperatively for monitoring and initiation of feeds.

A PEG may also be placed with laparoscopic assistance when anatomical variants and significant comorbidities preclude the conventional PEG insertion technique. Skin level 'button' gastrostomy tubes provide an easy and comfortable approach to enteral nutrition. Development of a single- stage percutaneous technique for gastrostomy button insertion rather than the two-stage technique is popular in some centres as are radiological techniques such as antegrade percutaneous fluoroscopically guided gastrostomy. An anti-reflux procedure (i.e. fundoplication) to decrease risk of aspiration due to gastric reflux may be done simultaneously with surgical gastrostomy. Image-guided gastrojejunal tubes may be a useful alternative to fundoplication and gastrostomy for neurologically impaired children with gastroesophageal reflux (GOR).

Benefits of gastrostomy tube feeding

In children with neurological impairment gastrostomy placement has been shown to significantly increase weight gain and to be associated with a reduction in all of the following: feeding time, drooling, feed-related choking episodes, vomiting, and frequency of chest infections. Malnourished children with severe CP show significant increases in body fat and protein with gastrostomy tube feeding. Such children have a rapid response to nutritional support through gastrostomy with catch-up growth regardless of age, even though there is a more pronounced state of malnutrition as age increases. Furthermore, death rates are distinctly higher in the subgroup of children with the most pronounced state of malnutrition and multiple secondary chronic conditions before gastrostomy.

Anecdotal reports in different studies, have suggested that early developmental progress, pubertal development and emotional temperament improved following gastrostomy feeding but this needs more detailed research.

Family stress is significantly reduced and quality of life of parents increases after gastrostomy insertion to assist feeding. Parents spend less time on child care once tube feedings are initiated and find feeding less difficult. This leads to evidence of caregiver satisfaction with gastrostomy tube feeding in the majority of studies.

Complications of gastrostomy tube feeding

It is difficult to make meaningful statements about risks and complications from the published data because types and rates of complications are not reported in a standard way and some children experience multiple complications. Insertion of a gastrostomy feeding tube carries with it a relatively low risk of complications. Published literature suggests a procedure-related mortality of 1%, a major complication rate of 3%, and a minor complication rate of 20%.

Reported major complications of gastrostomy insertion include adverse anaesthetic events, oesophageal laceration, pneumoperitoneum, peritonitis, colonic perforation and cologastric fistula formation. Many of these complications are now avoided or reduced in likelihood by refinements to the technique of insertion.

Later complications include stoma leakage, cellulitis, granulation tissue formation around the gastrostomy site and

