

## Special Article – Cerebral Palsy

# Enteral Tube Feeding in Children with Cerebral Palsy - Ethical Considerations

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Gastrostomy feeding is effective in reversing malnutrition in children with cerebral palsy (CP) and may have positive effects on the quality of life of the care givers. However, it is associated with several complications and it is costly. The supervision by qualified Nutrition Support Teams maximizes the effectiveness of this intervention, minimizing complications and/or costs.

Malnutrition in children with CP should be resolved and the nutritional status may be maintained with the means of gastrostomy feeding. Parents should be given detailed information to understand the principles, benefits, risks and alternatives of the proposed treatment as well as enough time to make an effective decision without any pressure from the health care professionals. The gastrostomies should be introduced by experienced endoscopists and the feeding should be supervised by qualified Nutritional Care Teams to maximize efficacy and minimize complications and/or costs.

**Keywords:** Cerebral Palsy; Gastrostomy; Enteral Tube Feeding; Ethics

## Introduction

Enteral tube feeding is frequently indicated in children with cerebral palsy (CP) with significant oropharyngeal incoordination who are unable to meet their nutritional requirements orally. This paper will consider the ethical issues related to enteral tube feeding in children with neurological impairment.

There is little or no information on this topic in the paediatric literature and much of what is written about the ethics of tube feeding centres on its use in end of life care in adults. The ethical principles, however, are the same.

The decision whether to employ a treatment is based on an evaluation of the likely net balance between the benefits and burdens and, therefore, introduces a concept of proportionality in promoting the best interest of the patient.

## Benefits of Gastrostomy Tube Feeding

Malnutrition is associated with multisystem impairment including immunosuppression and gastrointestinal dysfunction with an impact on the outcome of the underlying disease. In children with CP, mortality rates are distinctly higher in patients with the most pronounced state of malnutrition and multiple secondary chronic conditions, before the initiation of nutrition support with gastrostomy feeding [1]. Gastrostomy feeding has been shown to significantly increase weight gain [1] 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 [2]. Tube feeding in malnourished children with severe CP is associated with restoration of body composition with significant increases in body fat and lean body mass [1,3]. Such children have a rapid response to nutritional support through gastrostomy tube with catch-up growth regardless of age, even though there is a more pronounced state of malnutrition as age increases.

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.

Several studies have shown that 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 that leads to evidence of caregiver satisfaction with gastrostomy tube feeding [4]. Other studies however, claim no benefit [5] or even worse emotional functioning in parents of patients with CP fed via gastrostomy tube compared to parents of patients fed by mouth [6], as well as impaired social functioning of mothers of such patients, attributed to the lack of social support [7] which is an important factor that should be considered in the decision making for introducing PEG feeding.

## 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 [8]. 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, necrotising fasciitis, 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 displacement.

Gastrostomy site infection is the commonest problem occurring in up to 20% of cases but is easily and successfully treatable. More serious later complications such as bowel obstructions, buried bumper syndrome, gastrointestinal bleeds, ulceration, and peritonitis are rare. Other later gastrointestinal complications include constipation, diarrhoea, cramping, and vomiting. Gastrostomy insertion may worsen gastro-oesophageal reflux (GOR), necessitating the use of anti-reflux medication or surgery. The above symptoms in association with the inability of the patients to express thirst may result in metabolic complications due to fluid imbalance, particularly when high-calorie formulas are used for better weight gain. Furthermore, the excessive weight gain in this group of patients may cause difficulties in handling and lifting of the children, a problem that should not be overlooked when designing the tube feeding [9].

Death rates following gastrostomy range from 14% (after 1 year) to 26% (after 5 years). Most workers concur that these death rates are indicative of the severe morbidity (usually related to chronic secondary conditions including oesophagitis and lung disease from repeated pneumonias) in the children before gastrostomy [10].

## Autonomy

The benefit of enteral tube feeding is not determined solely by the potential medical benefits but also by the perceived benefits as determined by the child's designated surrogate decision maker. Such self-determination by a competent patient or a surrogate capable of making decisions is fundamental to the ethical principle of autonomy in which the individual has the right to determine his or her own destiny. Apart from the exceptional cases of child neglect or abuse, when conflicts arise between paediatrician and parents (as surrogate decision maker), patient autonomy takes precedence over clinician beliefs about beneficence. Nonetheless, the decision-making process for parents when a gastrostomy is first proposed is characterised by conflict [11]. Multiple negative perceptions may coexist in varying degrees and it is important for the clinician to appreciate parent perceptions about enteral tube feeding and especially gastrostomy tube feeding.

## Parents Perceptions

Application of a strict biomedical model with emphasis on growth and symptoms is likely to neglect parental concerns about gastrostomy tube feeding. Gastrostomy tube placement is often delayed due to negative caregiver perceptions [12]. This delay may occur despite multiple hospital admissions for respiratory infections due to aspiration. Paradoxically, these parents are often less tentative about allowing other more invasive procedures such as orthopaedic surgery.

Despite it being a struggle, mothers may view feeding by mouth as an enjoyable activity and an important social process. Mothers may feel guilty about their child's poor growth and may perceive the recommendation that gastrostomy feeding is required as confirmation of failure and a disruption of maternal nurturing and bonding. For some mothers gastrostomy feeding represents a loss of normality and may be seen as a confirmation of the permanence of the disability. In addition, the loss of oral feeding may be seen as a denial of a basic or essential human pleasure. Fears about loss of normal eating, dependency on gastrostomy feeds, complications of

the procedure and the like can make parents very resistant to the idea of gastrostomy tube feeding and, even if they agree, they may choose to use the gastrostomy only as a last resort [13].

Nonetheless, the majority of caregivers recognise improvement in the children following placement and show high levels of satisfaction. Importantly, the majority admit that they would have accepted an earlier placement of the gastrostomy tube had they anticipated the overall outcome [14,15]. Management of the affected child and family relationships are usually accepted as having improved considerably when the feeding difficulties are ameliorated by gastrostomy insertion.

## Informed and Educated Consent

From the foregoing it is clear that a great deal of sensitivity to the fears and feelings of the parents is required when approaching the subject of gastrostomy tube feeding. All members of the multidisciplinary team should be involved in the discussions on indications for and advantages and disadvantages of tube feeding in order to decide whether the patient is competent or not and convey a consistent message to parents. Parents need detailed information to understand the purpose of the proposed intervention, its principles, benefits, risks and alternatives as well as the consequences of not receiving the proposed treatment. In addition, they should be given enough time to retain the information in order to make an effective decision as result of free choice without any pressure from the health care professionals. Understanding the above perceptions [16] will help health-care workers to develop effective, family-centred, patient appropriate intervention and adherence strategies for gastrostomy fed children with CP. Only in this way will the important ethical principle of informed and educated consent be upheld.

## Finances of Gastrostomy Tube Feeding

Gastrostomy tube feeding is costly. Finances of this intervention should be another consideration in the decision making. Callahan et al reported a median annual cost of PEG feeding \$12,227 in US [17] while in UK, the cost of tube feeding in a disabled child costs between £3,000 to £5,000 per child per year (Sullivan: personal communication). Furthermore, a study in 33 adults in US who received PEG feeding due to dementia reported that 108 ambulance round trips to emergency room were required for surgical and/or gastroenterology consultations due to complications of PEG feeding, resulting in a total of \$86,234,48 hospital charges and in \$57,664 actual Medicare reimbursement for ambulance services [18]. In Europe, funding arrangements for home tube feeding differ from one country to another. In some European countries legislation either does not exist or it is restricted to certain diseases or conditions and in most countries there are no clear indications about disposables and infusion pumps.

## Supervision by Qualified Multidisciplinary Nutrition Care Teams (NCT)

In order to achieve maximum efficacy of the tube feeding with minimum complications and costs, the PEGs should be placed by experienced endoscopists and the feeding should be supervised by specifically trained personnel. Unfortunately, studies have reported gaps in the training in nutrition counseling in 86% of resident physicians in the US [19] and in 96% of GPs from those who referred adult patients with dementia for PEG placement in UK [20].

Furthermore, an expert report of the Council of Europe highlighted major deficits in nutritional care in European hospitals and provided recommendations for improving the situation, including the implementation of nutritional support teams [21] with the main goal of providing optimal nutrition to all patients [22]. The establishment of Nutritional Care teams has been shown to maximize the benefits of the nutrition support, minimize the risks of complications and/or the costs [23,24]. The ESPGHAN Committee on Nutrition recommends the implementation of NSTs in hospitals to improve nutritional management of sick children with main tasks to screen children for nutritional risk, identify patients who require nutritional support, provide adequate nutritional management, educate and train the hospital staff and carry out audit of practice. The NST should be multidisciplinary, with expertise in all aspects of clinical nutrition care and should be funded with funds raised from the health care system [25].

## Involvement of Children with CP in Research

There is an argument that the inability of vulnerable participants such as children with CP to provide complete consent represents a constraint on their freedom. These individuals are unable, through no fault of their own, to realise the full value of their rights. Although ethics committees are concerned about the potential for abuse and the legal implications of failure to protect participants, they have a further ethical obligation to make sure that such participants receive the full benefit of inclusion in research that may otherwise be beneficial to them. This is especially so in an era with rapid advances in knowledge about genetics, neurology, psychopharmacology and, indeed, nutritional management.

Disabled children are amongst the least privileged and most vulnerable in the community and if their circumstances are to improve, there is an urgent need to facilitate rigorous and ethical research into issues of importance to them, their families and their support systems.

## Conclusion

Although the hierarchy of research evidence underpinning the use of gastrostomy in children with neurodevelopmental problems may not be strong, it is important to appreciate that one of the central tenets of 'evidence-based medicine' is that evidence alone is never sufficient to make a clinical decision. A sound clinical decision is based upon the integration of the best available research evidence with clinical experience and patient values. This will involve a trade-off between benefits and risks, inconvenience and costs and the concerns, preferences and expectations of the patient/carer. When these elements are assimilated health care professionals and parents of children with CP can form a 'therapeutic alliance' to optimise growth, health and quality of life.

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