ORIGINAL ARTICLE

Does gastrostomy tube feeding in children with cerebral palsy increase the risk of respiratory morbidity?

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Background: Children with severe neurological impairment may have significant oral motor dysfunction and are at increased risk of nutritional deficiencies, poor growth, and aspiration pneumonia. Gastrostomy tube feeding is increasingly being used for nutritional support in these children.
Aim: To examine the occurrence of respiratory morbidity before and after gastrostomy feeding tube insertion in children with severe neurological disabilities.
Methods: This study was nested in a longitudinal, prospective, uncontrolled, multicentre cohort study designed to investigate the outcomes of gastrostomy tube feeding in 57 children with severe neurological disabilities. Parents completed a questionnaire prior to (visit 1) and 6 and 12 months (visits 2 and 3) following the gastrostomy, detailing number of chest infections requiring antibiotics and/or hospital admission.
Results: Mean number of chest infections requiring antibiotics was 1.8 on visit 1 and 0.9 on visit 3. Hospital admissions for chest infections fell significantly from 0.5 to 0.09.
Conclusion: This study provides no evidence for an increase in respiratory morbidity following insertion of a feeding gastrostomy in children with cerebral palsy.

Children with severe neurological impairment are at increased risk of growth disorders and nutritional deficiencies.[1 2] Gastrostomy tube feeding has been shown to lead to improved weight gain,[3–7] reduced feeding time,[8–10] and improved quality of life for carers.[9] Despite this evidence the decision for caregivers regarding the insertion of a gastrostomy tube can be a difficult one[11] with debate as to whether the benefits outweigh the risks.[12 13]

There are risks associated with gastrostomy feeding. Children with cerebral palsy (CP) are known to have reduced life expectancy and tube feeding has been identified as a risk factor for mortality in a number of studies.[14–16] Eyman *et al* found that those people who were so profoundly handicapped that they required tube feeding were surviving a mean of 4–5 more years and that respiratory illness was the most likely cause of death.[14] The cause of death in many children with CP is respiratory infection, but this group are already vulnerable to respiratory morbidity for several reasons.[17] Many have oral and pharyngeal dysfunction[18 19] leading to direct aspiration of secretions and foodstuffs, and they are known to become hypoxaemic during feeds, presumably secondary to aspiration.[20] Conversely, a normal swallowing mechanism has been shown to be protective with regard to respiratory morbidity.[21]

Strauss *et al* reported that gastrostomy tube feeding has a negative impact on survival of children with disabilities.[22] This was a retrospective analysis of 4921 children, which revealed a relative risk of mortality associated with tube feeding of 2.1. This relative risk was reduced if a tracheostomy was present and on further multivariate analysis, feeding tube use was associated with no identifiable increase in mortality in those with severe disabilities but, notably, a doubled mortality risk in those with less severe disability. They hypothesised that the increased mortality risk associated with tube feeding was attributable to respiratory disease secondary to overly vigorous nutritional maintenance and aspiration.

Our clinical experience did not concur with this. In a retrospective case note review following gastrostomy in 81 children with cerebral palsy, we found that in the 12 months following gastrostomy there was a reduction in documented bacterial chest infections from 37/81 (45.7%) to 26/81 (30.9%) ($p = 0.58$) and there was no difference in the number of hospital admissions for chest infection (11.1% *v* 12.3%).[23] Indeed there is evidence from other studies using retrospective questionnaires and semi-structured interviews which suggests that gastrostomy tube feeding leads to a decrease in chest infections,[8] direct aspiration,[24] and choking episodes.[8 10]

The aim of this study was to extend our observations by investigating in a prospective study whether the insertion of a gastrostomy feeding tube was associated with increased respiratory morbidity in children with severe neurological impairment.

METHODS

Study design

This study was nested in a longitudinal, prospective, uncontrolled, multicentre cohort study designed to investigate the outcomes of gastrostomy tube feeding in children with severe neurological disabilities.[7] Changes in outcome within participants were measured over time before and after insertion of a gastrostomy feeding tube. Use of a conventional control group for comparison was considered to be unethical since it would involve delaying intervention in a situation where it would be clinically indicated.

Setting

The study was set in specialist multidisciplinary feeding clinics for children with neurological disabilities in Oxford, Manchester, and Watford in the United Kingdom. Recruitment to the study commenced in December 1999 and ended in December 2002.

Participants
Children with cerebral palsy and nutritional problems secondary to oral-motor dysfunction for whom a gastrostomy was clinically indicated were eligible for entry to the study. Standardised indications for gastrostomy tube feeding across the centres included: (1) a severe degree of oral-motor dysfunction that was compromising nutritional status as indicated by body weight-for-age, triceps skin fold thickness for age; (2) clinical signs of under-nutrition (for example, wasting, and pale, cold, mottled skin of arms and legs); (3) prolonged (defined as > 6 weeks) dependence on nasogastric tube feeding; and (4) prolonged (defined as >3 hours/day) feeding. Exclusion criteria included: (1) the presence of evidence of genetic, metabolic, or neurodegenerative disease; and (2) children currently receiving corticosteroids or growth hormone therapy.

Intervention: gastrostomy placement
Those children in whom insertion of a gastrostomy tube was deemed clinically indicated underwent detailed preoperative workup. This included: (a) contrast videofluoroscopy analysis of their swallow to determine the degree of protection of the airway and the safety of the swallow; and (b) prolonged lower oesophageal pH monitoring to identify significant gastro-oesophageal reflux. Those without gastro-oesophageal reflux underwent standard percutaneous endoscopic gastrostomy. In those with a reflux index of greater than 10%[25] on pH monitoring, a laparoscopic fundoplication was performed at the same time as insertion of gastrostomy.

Assessment schedule
Children were assessed at three points: pre-gastrostomy tube insertion (visit 1), and 6 (visit 2) and 12 months (visit 3) afterwards. At visit 1, a detailed health history of the child was taken and information collected on neurological diagnosis and the extent of motor disability, medical history, growth patterns, and a detailed feeding history. In the medical history, particular attention was paid to a history of chest infection where the child was known to have been prescribed antibiotics for or was admitted to hospital with ''chest infection'' within the previous six months.

Table 1 Summary statistics for continuous variables (z scores are standardised for age and sex): average (median), proportion (%) of children more than 2 standard deviations below the mean (for z scores only), and range

	Baseline	
	n	Median (range)
Age	57	4.32 (0.44 to 17.28)
Weight (kg)	53	12.00 (5.11 to 35.11)
Weight, z score*	53	−3.03 (68%) (−14.54 to 2.05)
Occipito-frontal measurement, z score	50	−3.40 (80%) (−9.44 to 1.02)
Upper arm length, z score	29	−0.14 (24%) (−5.74 to 3.60)
Lower leg length, z score	31	−1.31 (39%) (−6.42 to 2.88)
Mid upper arm circumference, z score	49	−1.71 (33%) (−3.86 to 2.31)
Triceps skinfold thickness, z score	49	−0.93 (6%) (−2.22 to 1.51)
Subscapular skinfold thickness, z score	44	−0.42 (2%) (−1.37 to 1.85)

For reference ranges used, see Sullivan *et al.*[7]

At the follow up visits 6 and 12 months following insertion of gastrostomy, enquiry was made about problems with the gastrostomy and especially evidence of gastro-oesophageal reflux as well as the number of chest infections requiring either antibiotics or hospital admission since last seen. Careful physical examination of the chest was made at each clinical assessment. Hospital case records were also examined for each child to corroborate caregiver reports.

Statistical analysis
Data management, and descriptive and comparative statistical analyses were performed using SPSS for Windows (2002) and STATA (2002). Anthropometric data was expressed as standardised z scores of available age and sex specific reference population standards (a negative z score indicates below average).

Ethical approval
The Oxfordshire Clinical Research Ethics Committee granted ethical approval for this study. The carers of the children enrolled in the study provided informed, written consent before the initiation of the study.

RESULTS
Participants
Fifty seven patients participated in the study; their median age was 4 years 4 months, ranging from 5 months to 17 years 3 months. Poor nutritional state was the main reason for gastrostomy tube insertion; evidence for this can be seen in the anthropometric data shown in table 1. In table 1 in addition, for the standardised z scores, the proportion of children below a defined range expressed as a percentage are presented. We define the lower end of the defined range as a z score of −1.96 (that is, we would expect 2.5% of values to lay below this level) and the denominator for this percentage as the number of valid measurements.

Three quarters of the children enrolled (43/57) had spastic quadriplegic cerebral palsy. Other diagnoses included mixed (6/57), hemiplegia (3/57), undiagnosed severe neurological impairment (3/57), ataxia (1/57), and extrapyramidal disorder (1/57). Only 12% (7/57) could sit independently and only 5% (3/57) could walk unaided. Ninety three percent (53/57) of the children could not use their hands to feed themselves and 77% (44/57) were unable to grasp any object. In addition to these motor disabilities, 77% (44/57) exhibited profound/severe global developmental delay and learning difficulties and 67% (38/57) had some degree of visual impairment.

Gastrostomy placement
Fifty three children had percutaneous endoscopic gastrostomies (PEG) placed, while four had open gastrostomies. On the basis of identification of significant gastro-oesophageal reflux by prolonged lower oesophageal pH monitoring, 18/53 (34%) had a simultaneous laparoscopic fundoplication. There were no reported complications during gastrostomy placement. Some continued to have or developed minor symptoms suggestive of gastro-oesophageal reflux following gastrostomy tube insertion and all were managed successfully with proton pump inhibitor therapy. In none of the cases in this series was a fundoplication subsequently needed because of the development of gastro-oesophageal reflux secondary to gastrostomy tube placement.

Four of 57 patients (7%) died during the study, one prior to the insertion of a gastrostomy tube.

Respiratory morbidity
Following gastrostomy tube insertion there was a significant fall in the mean number of hospital admissions specifically

Table 2 Mean number of chest infections requiring antibiotics or hospital visits as reported by the child's primary caregiver in the six months prior to visits 1, 2, and 3

	Visit 1 (n = 57)	Visit 2 (n = 47)	Visit 3 (n = 45)	*t* test p value*
Infections requiring antibiotics				
Mean no. (SD)	1.8 (2.7)	1.0 (1.8)	0.9 (1.7)	0.07
Median	1.00	0.00	0.00	
Infections requiring hospital admission				
Mean no. (SD)	0.5 (1.0)	0.3 (0.7)	0.09 (0.4)	0.04
Median	0.00	0.00	0.00	

*Visit 1 to visit 3.

for chest infection (paired sample *t* test: p = 0.04) and a non-significant fall in mean number of courses of antibiotics (paired sample *t* test: p = 0.07) specifically prescribed for chest infections (table 2). There was no significant difference in courses of antibiotics or hospital admissions between those who did and did not have a fundoplication.

Forty four children underwent contrast videofluoroscopy to investigate the clinical suspicion of aspiration/penetration from failure to protect the airway during swallowing (''unsafe swallow'') and this abnormality was confirmed in 16 cases. At baseline, 10/16 (62.5%) had one or more chest infections requiring antibiotics in the previous six months. Similarly, 7/16 with an unsafe swallow had required hospitalisation for chest infection(s) within the six months prior to gastrostomy insertion. Following gastrostomy there was a fall in the proportion of children with a proven unsafe swallow requiring either antibiotics or hospital admission for chest infection at follow up at 6 and again at 12 months (table 3). Twelve months post-gastrostomy no child had been admitted to hospital for chest infection in the previous six months and there was no significant difference between the proportions of children with safe or unsafe swallows requiring antibiotics for chest infection (χ^2 test: p = 0.42).

In order to address the question of the role of concomitant fundoplication performed with gastrostomy contributing to the protection against respiratory infections, data from those with and without fundoplication are presented (table 4). There is no evidence form this analysis that the absence of an increase in respiratory morbidity following gastrostomy insertion is attributable to protection from significant gastro-oesophageal reflux secondary to a surgical anti-reflux procedure. At 12 months following surgery, for instance, there was no significant difference in the proportions of children with or without fundoplication who had required antibiotics in the previous six months (χ^2 test: p = 0.43) and in both groups no child had been admitted to hospital during this period.

DISCUSSION

Strauss first raised the prospect that tube feeding in children with neurological impairment might be associated with an increased mortality due to aspiration.[22] Given the increasing frequency with which tube feeding is employed in such children, this becomes an issue of considerable practical importance. Cass *et al*, in a recent review, identified the need for prospective studies to improve the evidence base with respect to the pulmonary consequences of dysphagia in children.[26] The present study is the first to attempt to address this issue by looking for evidence of respiratory morbidity in children before and after insertion of a gastrostomy feeding tube. No evidence of an increase in respiratory morbidity has been found in the 12 months following insertion of a gastrostomy feeding tube. In fact, a significant reduction in the number of courses of antibiotics for chest infections was detected a year after gastrostomy.

Four of our 57 patients (7%) died and in order to interpret this one needs to know the mortality rates in similar populations; Eyman *et al* reported a median survival of 4.8 years for immobile tube fed children and 10.9 years for those with limited mobility.[15] Another population based study of gastrostomy tube fed children with CP found a one year survival of 91%, a two year survival of 83%, and four year survival of 76%,[24] while a survival analysis of non-institutionalised children with severe CP following gastrostomy revealed that 84.2% were alive a year following surgery and 73.5% at two years.[27] Therefore the mortality figures in our cohort of predominantly severely disabled children are comparable to other studies.

The present study also highlights the relationship between the safety of swallow and the role of direct antegrade aspiration (DA) in respiratory morbidity in children with CP. Oral motor dysfunction (OMD) is a common problem in children with severe neurodisability; more than 90% of children with CP have evidence of clinically significant OMD.[18] Depending on the degree of disability, DA can be found in as many as 38% of children with CP and occurs at any stage in the swallowing process.[28] Morton *et al* studied a group of children with neurodisability; in those with recurrent respiratory tract infections (n = 16), one had gastro-oesophageal reflux alone, seven had DA alone, and eight had both, while in those with no respiratory infections (n = 10), none had DA.[21] They concluded that OMD and subsequent DA is the major cause of respiratory morbidity in this group of children. Our findings concur with this as the insertion of a gastrostomy tube (invariably accompanied by a reduced oral intake) led to an apparent reduction in chest infections in those who had a proven unsafe swallow.

Gastro-oesophageal reflux is common in children with CP and, in some patients, the insertion of a gastrostomy feeding

Table 3 The effect of swallow safety as judged by contrast videofluoroscopy on respiratory morbidity

	Baseline		6 months		12 months	
	Unsafe	Safe	Unsafe	Safe	Unsafe	Safe
% (no.) with 1 or more chest infections requiring antibiotics	62.5 (10/16)	50.0 (14/28)	46.7 (7/15)	45.0 (9/20)	27.3 (3/11)	42.1 (8/19)
% (no.) with 1 or more chest infections requiring hospital admission	43.8 (7/16)	21.4 (6/28)	20.0 (3/15)	15.0 (3/20)	0.0 (0/11)	0.0 (0/19)

Table 4 The effect of fundoplication on respiratory morbidity

	Baseline		6 months		12 months	
	Fundoplication	No fundoplication	Fundoplication	No fundoplication	Fundoplication	No fundoplication
% (no.) with 1 or more chest infections requiring antibiotics	50.0 (8/16)	50.0 (11/22)	50.0 (8/16)	36.4 (8/22)	41.7 (5/12)	27.8 (5/18)
% (no.) with 1 or more chest infections requiring hospital admission	37.5 (6/16)	27.3 (6/22)	25.0 (4/16)	9.1 (2/22)	0.0 (0/12)	0.0 (0/18)

tube can create or exacerbate this condition.[6 8] One third of the patients required a surgical anti-reflux procedure at the same time as gastrostomy insertion and this proportion reflects the level of disability and degree of foregut dysmotility in our referral population of children with severe cerebral palsy. All children who underwent fundoplication had a reflux index of over 10%[25] (the upper limit of normal is in fact 5%) on prolonged lower oesophageal pH study, a failure to tolerate a trial of nasogastric tube feeding and, in some instances, also failure to control symptoms by proton pump inhibitor therapy. No patient in this series developed post-gastrostomy gastro-oesophageal reflux that was not adequately controlled by antacid therapy and no additional anti-reflux procedures were performed. There is evidence that improvement in nutritional status (as occurred after gastrostomy tube feeding in this group)[7] can be associated with amelioration of gastro-oesophageal reflux[29] and in a reduction in respiratory morbidity;[30] such an effect may have contributed to airway protection in our cases. There was consistently no significant difference in number of chest infections between those who had an anti-reflux procedure and those who did not. This, together with our findings regarding safety of swallow, suggests that the respiratory pathology to which this group of children are vulnerable is more likely to be a result of DA than gastro-oesophageal reflux.

Interpretation of these results must take into account the limitations of the study. As this investigation took place in the context of a larger study into the effectiveness of gastrostomy tube feeding in children with cerebral palsy, the study design was pragmatic with each case in the cohort acting as their own control. We have discounted as unethical the possibility of a formal randomised controlled trial as a potential study design but it may be that a differently designed study with a conventional age, sex, and disability matched control for each child undergoing gastrostomy intervention might come to a different conclusion. Although detailed investigations were undertaken to identify oropharyngeal aspiration during swallowing and pathological gastro-oesophageal reflux, we did not undertake detailed pulmonary imaging (for example, high resolution chest computerised tomography and/or ventilation-perfusion scanning) which might have identified the effects of ''silent aspiration''.[28 31] Another limitation to this prospective study is that the sample size is relatively small and lacks power to detect significant differences between the different groups; we have calculated that we would need approximately 200 cases per group to achieve 90% power; such a study would be very difficult to undertake in this group of severely disabled children. These limitations notwithstanding, when the observations from our retrospective case note review are included, we have now examined for and failed to find an association between respiratory morbidity and gastrostomy feeding in a total of 138 children with neurological impairment.[23]

What is already known on this topic

- Gastrostomy tube feeding has been shown to be an effective intervention for feeding problems in children with neurological impairment but may exacerbate gastro-oesophageal reflux
- It has been suggested that excess mortality and morbidity from respiratory complications may accompany tube feeding in these children

What this study adds

- No evidence of an increase in respiratory morbidity has been found in the 12 months following insertion of a gastrostomy feeding tube
- Insertion of a gastrostomy tube (invariably accompanied by a reduced oral intake) led to an apparent reduction in chest infections in those who had a proven unsafe swallow and were unable to protect their airway during feeding

Conclusion

In this longitudinal, prospective, uncontrolled, multicentre cohort study we have failed to find any evidence of increased respiratory morbidity in children with cerebral palsy secondary to insertion of a gastrostomy feeding tube.

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