Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study

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We report a longitudinal, prospective, multicentre cohort study designed to measure the outcomes of gastrostomy tube feeding in children with cerebral palsy (CP). Fifty-seven children with CP (28 females, 29 males; median age 4y 4mo, range 5mo to 17y 3mo) were assessed before gastrostomy placement, and at 6 and 12 months afterwards. Three-quarters of the children enrolled (43 of 57) had spastic quadriplegia; other diagnoses included mixed CP (6 of 57), hemiplegia (3 of 57), undiagnosed severe neurological impairment (3 of 57), ataxia (1 of 57), and extrapyramidal disorder (1 of 57). Only 7 of 57 (12%) could sit independently, and only 3 of 57 (5%) could walk unaided. Outcome measures included growth/anthropometry, nutritional intake, general health, and complications of gastrostomy feeding. At baseline, half of the children were more than 3SD below the average weight for their age and sex when compared with the standards for typically-developing children. Weight increased substantially over the study period; the median weight *z* score increased from –3 before gastrostomy placement to –2.2 at 6 months and –1.6 at 12 months. Almost all parents reported a significant improvement in their child's health after this intervention and a significant reduction in time spent feeding. Statistically significant and clinically important increases in weight gain and subcutaneous fat deposition were noted. Serious complications were rare, with no evidence of an increase in respiratory complications.

There is a high prevalence of oral-motor dysfunction in children with severe neurological impairment. Previous research by the Oxford Paediatric Nutrition Group revealed that in a group of such children, 238 of 268 (89%) needed help with feeding and 142 of 257 (55%) regularly choked during feeding (Sullivan et al. 2000). Strong associations were found between the degree of motor impairment, severity of feeding difficulties, and nutritional inadequacies (Sullivan et al. 2002). Oral-motor dysfunction has been shown to be associated with poor growth, poor nutritional status, and poor health status by numerous research groups (Dahl et al. 1996, Reilly et al. 1996, Fung et al. 2002).

Enteral feeding via gastrostomy tube is increasingly being used to provide nutrition to children with oral-motor dysfunction and feeding problems. Moreover, tube feeding is more likely to be initiated in children with a severe disability (Sullivan et al. 2002), and reports from various groups have indicated that both growth and nutritional status improve after enteral feeding (Patrick et al. 1986, Sanders et al. 1990, Corwin et al. 1996, Brant et al. 1999).

The most recent systematic review of gastrostomy feeding in children with disabilities, however, concluded that there is considerable uncertainty about its safety and efficacy (Samson-Fang et al. 2003). The quality of research on which efficacy of this nutritional intervention is based is limited to retrospective studies of small series from single centres, and there has been no longitudinal, prospective study of gastrostomy tube feeding in this group of children. Moreover, complications of gastrostomy feeding have been described in 4 to 26% of cases (Gauderer 1988, Marin et al. 1994). Strauss et al. (1997) have also suggested that there might be an increased mortality associated with tube feeding even in those children with less severe motor disabilities. It was in response to the need for more prospective clinical data on gastrostomy tube feeding that the present study was undertaken.

The primary aim of this study, therefore, was to evaluate the growth and nutritional status of children with severe neurological disabilities before and after gastrostomy placement.

Method

STUDY DESIGN

This was a longitudinal, prospective, uncontrolled multicentre cohort study designed to investigate the outcomes of gastrostomy tube feeding in children with a severe neurological disability. Changes in outcome within participants were measured before and after the insertion of a gastrostomy feeding tube. The use of a conventional control group for comparison was considered to be unethical because it would involve delaying intervention in a situation in which 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, UK. Recruitment to the study began in December 1999 and ended in December 2002.

PARTICIPANTS

Children with cerebral palsy (CP; as defined by Bax, 1964) and nutritional problems secondary to oral-motor dysfunction for whom a gastrostomy was clinically indicated were eligible for entry to the study. Standardized 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 and triceps skinfold thickness for age, and (2) clinical signs of undernutrition, such as wasting, or pale, cold mottled skin of arms and legs.

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 clinically indicated underwent a 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 prolonged lower oesophageal pH monitoring to identify significant gastroesophageal reflux. Those without gastroesophageal reflux underwent standard percutaneous endoscopic gastrostomy. In those with a reflux index of greater than 10% on pH monitoring (Sullivan 1999), a laparoscopic fundoplication was performed at the same time as insertion of gastrostomy.

All children were fed with a proprietary enteral tube feed (Nutrison; Nutricia Clinical Care Ltd, Wiltshire, UK) with an energy density of 1kcal/ml. The amount of feed prescribed was approximately 75 to 80% of the estimated average requirement for energy for the age for each child (Department of Health 1991) to compensate for the reduction in energy expenditure in immobile children with CP in comparison with their typically-developing peers. Continuation of oral feeding was encouraged, to allow ongoing experience of taste and texture for each child; in those with an unsafe swallow, thickening of feeds was recommended to aid airway protection.

OUTCOME MEASURES

Primary outcome measures were growth and anthropometry. Secondary outcome measures were nutritional intake, general health, and complications of gastrostomy feeding.

ASSESSMENT SCHEDULE

Children were assessed on three occasions: at baseline, namely before gastrostomy placement (visit 1), and at 6 (visit 2), and 12 months (visit 3) after gastrostomy placement. Visits took place either in the local hospital or at the child's home. To ascertain how weight had been changing before gastrostomy placement, additional body weight data were collected retrospectively from medical records going back as far as 12 months, where possible.

GROWTH

Growth was measured in the following ways. Body weight was measured using seated electronic weighing scales (the same scales at each visit), with the child wearing light indoor clothing. Occipito-frontal circumference was measured with a tape measure (Lasso headtape measure; Child Growth Foundation, London, UK). Left lower leg length and left upper arm length were determined with a Harpenden anthropometer (Child Growth Foundation).

As specific measures, left triceps and subscapular skinfold measurements were taken with skinfold callipers (Holtain Ltd, Crymmych, Pembrokeshire, UK). To reduce measurement error, each measurement was taken in triplicate by the same observer in each centre and an average of the three was calculated.

NUTRITIONAL INTAKE

Dietary intake data were collected at baseline and again after 6 and 12 months. As in our previous work (Sullivan et al. 2002), carers used a 3-day dietary diary to record all food and drink consumed by their child. The diary contained simple written instructions and a questionnaire on commonly used proprietary foods, cooking methods, food consistency, and supplements. Carers were also given verbal instruction on how to complete the diary. It was emphasized that the amount actually eaten by the child should be recorded, not the amount offered or spilled. Discrepancies in recorded data were resolved by interview with the carer. Dietary intake data were analyzed with Dietplan 5™ software (Forestfield Software Ltd, Horsham, UK). All dietary intake data were expressed as a percentage of the dietary reference values for food energy and nutrients for the UK (adjusted for each child's age and sex; Department of Health 1991) or as kcal per kilogram of body weight.

GENERAL HEALTH

At baseline (gastrostomy placement) a detailed health history of the child was taken. Information was collected on neurological diagnosis, medical history, growth patterns, and extent of motor disability. At visits 2 and 3 (6 and 12 months after gastrostomy insertion respectively) enquiry was made about problems with the gastrostomy, the current feeding regime, carer perceptions of growth, and the impact of the gastrostomy on the child and family.

Measuring the general health status of children with severe disabilities is difficult because of their inability to communicate and their numerous and complex medical problems. Respiratory symptoms are common in such children and are a source of concern to carers. Thus, as proxy measures of general health in this group of children, carers were also asked to report the number of chest infections requiring either antibiotics or hospital admission in the previous 6 months at baseline and visits 2 and 3.

Oxfordshire Clinical Research Ethics Committee granted ethical approval for this study. Carers of the children enrolled provided written informed consent before the children could be entered into the study.

STATISTICAL ANALYSIS

Data management and descriptive and comparative statistical analyses were performed with SPSS for Windows (version 11.5) and STATA (version 7). The target sample size of 75 children was based on a pragmatic assessment of expected recruitment within the given time period. Given the limited numbers of children with this clinical disposition, this approach was preferred to a formal statistical calculation.

To facilitate internal and external comparisons adjusting for the known confounding effects of age and sex, measurements were expressed as standardized z scores of available age and sex-specific reference population standards (a negative z score indicates a below average result). For weight and occipito-frontal circumference, measurements were standardized to the 1990 British Growth reference centiles (Freeman et al. 1995). Upper arm and lower leg length

measurements were standardized to American reference standards because none is available for British children (Spender et al. 1989), and mid-upper-arm circumference and skinfold measurements were standardized to American data (Frisancho 1988).

The continuous variables age, weight, and standardized *z* scores were investigated for departure from normality both informally, by assessing the distribution when looking at a histogram, and formally, using the Shapiro–Wilk test for normality. Most children were in the lowest centiles for their measurements and, therefore, the data were very skewed. It was decided to present the median and the range as descriptive statistics (Table I). In addition, for the standardized *z* scores we present the proportion of children below a defined range expressed as a percentage (Table I). We define the lower end of the defined range as a *z* score of –1.96 (i.e. we would expect 2.5% of values to lie below this level) and the denominator for this percentage as the number of valid measurements. We acknowledge that 1.96 is an arbitrary cut-off (representing approximately two standard deviations [SD] below the mean) and that some children did indeed register measurements above a *z* score of 1.96; however, the focus of this study is the lower end of the weight spectrum and, hence, a one-sided aspect is presented here.

To describe the change in growth indices in the 12-month period after gastrostomy, we calculated empirical centiles of the distribution of the change: 5th, 25th (lower quartile), 50th (median), 75th (upper quartile) and 95th (Table II). In addition, being aware that not all children might benefit from the intervention, we also calculated the absolute number of children (percentage) with an increase in *z* score. To evaluate changes in growth indices over time, we performed the non-parametric Wilcoxon signed-ranks test on the change over 12 months. Corresponding 95% confidence intervals (CI) for the median change were calculated by using the binomial method (Conover 1980).

Nutritional intake data were evaluated (median, range) for energy, protein, carbohydrate, fat, and fibre because tests for normality revealed that the data were skewed.

To investigate potential improvements in general health in this group of children, the change in the number of children with chest infections requiring either antibiotics or hospital admission (in the previous 6 months) comparing 12 months with baseline was evaluated with McNemar's χ^2 test.

Results

DEMOGRAPHIC CHARACTERISTICS AND CLINICAL PRESENTATION BEFORE GASTROSTOMY PLACEMENT

Fifty-seven children with CP (28 females, 29 males) were enrolled in the study (Oxford, n=41; Manchester, n=9; Watford, n=7). Median age of the children was 4 years 4 months; range 5 months to 17 years 3 months. Three-quarters of the children enrolled (43 of 57) had spastic quadriplegic CP; other diagnoses included mixed CP (6 of 57), hemiplegia (3 of 57), undiagnosed severe neurological impairment (3 of 57), ataxia (1 of 57), and extrapyramidal disorder (1 of 57). Only 7 of 57 (12%) could sit independently and only 3 of 57 (5%) could walk unaided. Nearly all of the children (53 of 57) could not use their hands to feed themselves, and 44 of 57 (77%) were unable to grasp any object (equivalent to level V on the Gross Motor Function Classification scale; Palisano et al. 2000). In addition to motor disabilities, 44 of 57 (77%) children exhibited profound or severe global developmental delay and learning disability* and two-thirds (37 of 55) had some degree of visual impairment.

Oral-motor problems were common. Nearly half (25 of 54) of the children had significant tongue thrust and 19 of 54 (35%) had tonic jaw biting, which impaired oral feeding.

*US usage: mental retardation.

Table I: Summary statistics for continuous variables for participants

Measurement	*Baseline*		*6 months after GS*		*12 months after GS*	
	n	*Median (range)*	*n*	*Median (range)*	*n*	*Median (range)*
Age, y	57	4.32 (0.44 to 17.28)	46	4.72 (0.97 to 18.02)	44	4.86 (1.48 to 18.53)
Weight, kg	53	12.00 (5.11 to 35.11)	45	14.10 (6.49 to 45.35)	46	15.55 (7.98 to 55)
Weight, *z* score[a]	53	–3.03 (68%) (–14.54 to 2.05)	45	–2.23 (53%) (–11.95 to 1.33)	46	–1.60 (48%) (–11.71 to 2.32)
Occipito-frontal measurement, *z* score[a]	50	–3.40 (80%) (–9.44 to 1.02)	43	–3.76 (74%) (–8.68 to 0.80)	43	–3.67 (71%) (–8.14 to 0.52)
Upper arm length, *z* score[b]	29	–0.14 (24%) (–5.74 to 3.60)	28	0.33 (14%) (–7.33 to 2.06)	31	0.58 (13%) (–7.0 to 4.3)
Lower leg length, *z* score[b]	31	–1.31 (39%) (–6.42 to 2.88)	30	–0.75 (33%) (–6.82 to 2.3)	32	–0.44 (19%) (–5.73 to 5.42)
Mid-upper-arm circumference, *z* score[c]	49	–1.71 (33%) (–3.86 to 2.31)	45	–1.29 (20%) (–3.53 to 2.27)	46	–0.59 (14%) (–3.28 to 2.79)
Triceps skinfold thickness, *z* score[c]	49	–0.93 (6%) (–2.22 to 1.51)	44	–0.53 (5%) (–2.14 to 2.45)	45	–0.74 (2%) (–2.04 to 2.93)
Subscapular skinfold thickness, *z* score[c]	44	–0.42 (2%) (–1.37 to 1.85)	40	–0.19 (0%) (–1.29 to 2.87)	40	–0.07 (0%) (–1.25 to 3.86)

z scores are standardized for age and sex. Results shown are median (percentage of children more than 2SDs below mean [for *z* scores only]) and range. GS, gastrostomy. [a]Reference population: 1990 British growth reference centiles (Freeman et al. 1995). [b]Reference population: Spender et al. (1989). Note that reference data start at age 3 years. [c]Reference population: Frisancho (1988).

Half (28 of 57) had experienced feeding difficulties from birth. Potentially dangerous symptoms associated with oral feeding included 27 of 57 (47%) children 'always coughing' and 23 of 57 (40%) frequently choking. Common problematic feeding behaviours reported included 'turns head away' in 22 of 55 (40%), 'easily distracted whilst feeding' in 13 of 55 (24%), and 'food refusal' in 24 of 55 (44%).

Epilepsy was present in just over half the children (31 of 55). Two-thirds of the children had microcephaly (36 of 54), scoliosis was present in 20 of 57 (35%), and hip dislocation in 17 of 57 (30%). Figure 1 shows the patient flowchart and reasons for attrition for those children who were lost to follow-up. Dropout was caused mainly by logistical difficulties rather than being related to gastrostomy, and so we do not expect this to have imparted any significant bias.

GASTROSTOMY PLACEMENT

Fifty-three children had a percutaneous endoscopic gastrostomy placed, two had laparoscopic assisted gastrostomies, and two had open gastrostomies. On the basis of identification of significant gastroesophageal reflux by prolonged monitoring of lower oesophageal pH, 18 had a simultaneous laparoscopic fundoplication. There was no reported complication during gastrostomy placement.

GROWTH AND ANTHROPOMETRY

Table I shows summary statistics for the measurements recorded for the participants at each time point, and Table II shows summary statistics for the change in *z* score between baseline and 12 months after gastrostomy. Figure 2 specifically illustrates weight *z* score at each of the three study visits. Figure 2 is a dot plot that presents all of the raw data, with the added features of a horizontal line representing the median value for the reference population (i.e. *z* score=0), and a shorter horizontal line indicating the median at each time point.

At baseline, half of the children were more than 3SD below the average weight for their age and sex, in comparison with the standards for typically-developing children; we would typically expect a figure of about 0.2% (1 in every 500). Weight increased substantially over the study period; the median weight *z* score increased from –3 before gastrostomy placement to –2.2 at 6 months after placement and –1.6 at 12 months (Table I, Fig. 2). The proportion of children more than 2SD below the mean dropped from two-thirds at baseline to just under a half at 12 months. To put this in perspective, we would expect this proportion to be about 2.5% (1 in every 40). This corresponds to a highly statistically significant median change (increase) in *z* score over 12 months (Table II) of 1.24 (95% CI 0.88 to 1.6; $p<0.0001$). Indeed, 9 out of every 10 participants (42 of 46) had an increase in weight *z* score; that is, their weight increased over and above the weight gain that one would expect over a year; this is all the more impressive when

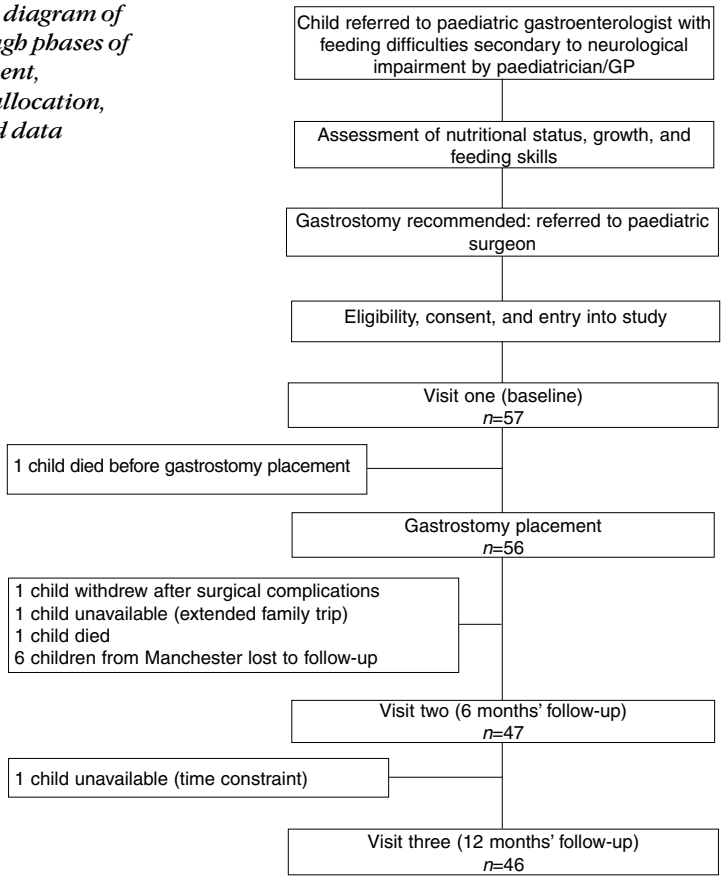

Figure 1: *Flow diagram of progress through phases of study (enrolment, intervention allocation, follow-up, and data analysis).*

considering that the reference population are children without disability.

Head growth (occipito-frontal circumference) was also significantly impaired in these children with median *z* scores at baseline, 6, and 12 months of –3.4, –3.76, and –3.67 respectively. Almost three out of every four (31 of 43) participants for whom 12 months' follow-up data were available showed an increase in head circumference *z* score; this corresponded to a statistically significant median change in *z* score over 12 months of 0.31 (0.15 to 0.52; $p=0.004$). At baseline, four out of five children were below our defined threshold of 2SD below the mean, and at 12 months this figure had improved slightly to 71%.

Linear growth, as measured by upper arm and lower leg limb length, was similar but less impaired at baseline, and it is noteworthy that the compromise in linear growth was more marked in the lower limb. For lower leg length, the baseline median *z* score of –1.31 improved to –0.44 at 12 months, again a highly statistically significant median change (increase) in *z* score of 0.8 (95% CI 0.26 to 1.37; $p=0.003$). The proportion of children more than 2SD below the reference mean value halved over 12 months from 39% to 19%. In the upper arm, the median baseline *z* score was close to the population norm at –0.14, again improving to 0.58 at 12 months, indicating that most children were above average at that juncture. The proportion of children more than 2SD below the reference mean value approximately halved over 12 months from 24 to 13%. We should note here that the reference population for linear growth is a CP population and that the reference data start at age 3 years, which accounts for the smaller numbers in Tables I and II for these particular measurements.

In summary, when compared with a reference population of similar children, two out of every three children increased their upper arm length *z* score, and three-quarters increased their lower leg length *z* score.

Ponderal measurements of mid-upper-arm circumference, triceps and subscapular skinfold thickness all showed highly statistically significant increases over 12 months, with about four out of every five participants showing an increase in *z* score.

The most marked improvement was in mid-upper-arm circumference. Baseline median mid-upper-arm circumference *z* score was very low at –1.71, with one out of every three children scoring more than 2SD below the reference mean. At 12 months, the median mid-upper-arm circumference *z* score had improved to –0.59, and the proportion of children scoring more than 2SD below the reference mean had diminished to a respectable 14%. The median change (increase) in *z* score for mid-upper-arm circumference. was estimated as 1.02 (95%CI 0.49 to 1.60; $p<0.0001$). This is the second largest increase, but perhaps not unexpected because mid-upper-arm circumference. is highly correlated with weight.

As for triceps and subscapular skinfold thickness, the median *z* scores for both these measurements indicated a significant improvement from baseline to 12 months after gastrostomy. However, it seemed that the main improvements were made predominantly in the first 6-month period.

In summary, clinically important and statistically significant improvements were made on all growth and anthropometric measures. In most cases, the improvements were sustained and similar over the two consecutive 6-month periods.

Table II: Summary statistics (centiles) for change in *z* score plus number (%) of children with an increase in *z* score between baseline and 12 months after gastrostomy

Measurement	*n*	*Centile*					*Number (%) of children with an increase in z score*
		5th	*25th*	*50th (p)*	*75th*	*95th*	
Weight	46	–0.41	0.66	1.24 (<0.0001)	1.88	4.79	42 (91)
Occipito-frontal measurement	43	–1.01	–0.10	0.31 (0.004)	0.66	1.39	31 (72)
Upper arm length	23	–0.79	–0.25	0.54 (0.031)	1.04	2.36	15 (65)
Lower leg length	25	–1.00	0.01	0.80 (0.003)	1.42	2.37	19 (76)
Mid upper arm circumference	42	–0.34	0.21	1.02 (<0.0001)	1.87	3.29	34 (81)
Triceps skinfold thickness	41	–0.67	0.04	0.35 (0.001)	0.90	1.68	32 (78)
Subscapular skinfold thickness	36	–0.65	0.01	0.30 (0.0004)	1.24	2.91	28 (78)

p values are from a Wilcoxon signed-ranks test.

Table III: Energy, macronutrient, and fibre intake of children at baseline and 6 and 12 months after gastrostomy

Measurement	*Baseline, n=43*	*6 months after GS, n=36*	*12 months after GS, n=27*
Energy, %drv	66 (7), 22–148	73 (22), 39–198	70 (15), 43–116
Protein, %drv	137 (74), 37–273	156.5 (75), 52–388	154 (89), 64–307
Carbohydrate, %drv	51 (2), 14–134	56 (3), 28–171	58 (0), 30–92
Fat, %drv	73 (26), 19.7–141	84.8 (36), 15–213	82 (33), 37–147
Fibre, g	0, 0–11.2	0.2, 0–23	0.8, 0–14.6

Results are medians (percentage of children with at least 100% dietary reference value) and ranges.
%drv, percentage of dietary reference value (Department of Health 1991); GS, gastrostomy.

NUTRITIONAL INTAKE

Dietetic analysis (Table III) confirmed, as we have shown in a previous study (Sullivan et al. 2002), that at baseline, on average, energy, carbohydrate, fat, and fibre intakes were lower than recommended. Indeed, only protein intake was regularly above the reference nutrient intake (Department of Health 1991). Over the 12-month period there was a measurable increase in energy intake, which was predominately associated with an increase in fat intake rather than an increase in carbohydrate intake.

GENERAL HEALTH

The proportion of children with at least one infection (in the previous 6 months) requiring hospitalization dropped from 11 of 43 (26%) at baseline to 3 of 43 (7%) at 12 months after gastrostomy ($p=0.021$). However, the proportion of children with at least one infection (in the previous 6 months) requiring antibiotics remained constant, at around the 40% mark. The findings were similar in those children with or without a fundoplication.

COMPLICATIONS OF GASTROSTOMY FEEDING

The complications arising from gastrostomy feeding are shown in Table IV. One child experienced serious complications after surgery: one week after his laparoscopic fundoplication he was readmitted with gastric leakage, peritonitis, and skin erythema, excoriation, and ulceration. These complications were not resolved medically, so the gastrostomy site was surgically closed and he was fed through a nasogastric tube until a laparoscopic assisted gastrostomy was placed 18 months later.

By the second visit (6 months after gastrostomy placement) half (24 of 47) of the children had had their gastrostomy tube changed to a skin-flush button device. By 12 months after gastrostomy insertion, three-quarters (34 of 46) had had a button placed. In none of the cases in this series was a fundoplication needed because of the development of gastroesophageal reflux secondary to gastrostomy tube placement.

Discussion

Long-term follow-up studies (e.g. Gauderer et al. 1988) have shown that percutaneous endoscopic gastrostomy is a safe, efficient, and cost-effective feeding technique. Nevertheless, major complications can occur during or shortly after insertion of percutaneous endoscopic gastrostomy; they include the risk from anaesthesia, laceration of the oesophagus, pneumoperitoneum, peritonitis, and colonic perforation with the risk of formation of a colo-gastric fistula (Bender and Levison 1991). Minor complications, such as stoma leakage, cellulitis, and the formation of granulation tissue around the site of insertion of percutaneous endoscopic gastrostomy, usually occur at a later stage. The most common long-term complication of gastrostomy is leakage of gastric contents, leading to discomfort arising from erosion of the skin. In addition, gastroesophageal reflux can increase after tube placement (Coben et al. 1994). Various research groups have debated the impact of gastrostomy tube feeding on the mortality risk of children with neurological disabilities. An association between the presence of a feeding tube and increased mortality risk in children with disabilities has been suggested (Eyman et al. 1990, Kastner 1992, Kastner et al. 1994). Strauss et al. (1997) have suggested that there might be an increased risk of mortality associated with tube feeding even in those children with less severe motor disabilities. They hypothesized that the increased mortality associated with tube feeding might be attributable to a differential increase in pulmonary disease secondary to overly vigorous nutritional maintenance and subsequent aspiration after tube placement. They went on to suggest that given the observed higher mortality rates among tube-fed children with less severe disabilities and the substantial costs associated with tube feeding, a prospective, controlled study might be clinically indicated, ethically justifiable, and economically warranted.

We did not consider a randomized controlled trial to be ethical or feasible, and opted for a longitudinal, prospective cohort study design. The children with CP in this study had a severe degree of motor disability, with 95% unable to walk

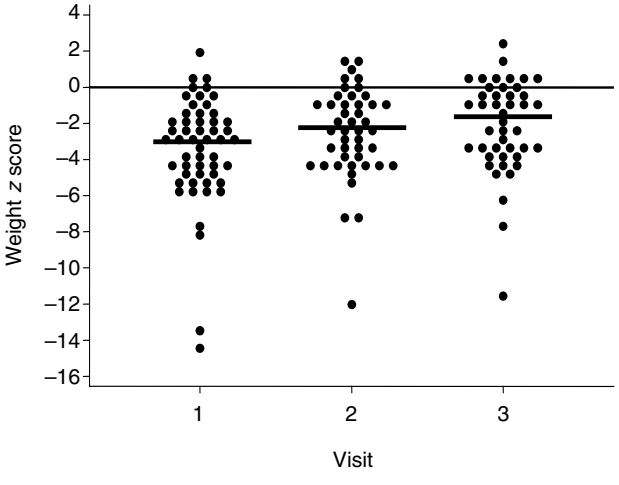

Figure 2: *Dot plot of body weight z score at each time point.*

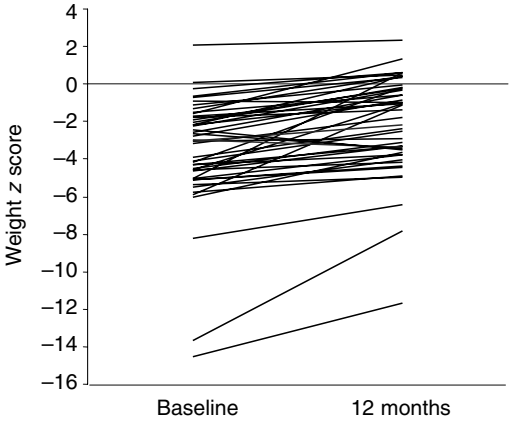

Figure 3: *Weight z score before and 12 months after gastrostomy.*

independently and accompanied by both marked oral-motor impairment and feeding difficulty. This feeding difficulty was a source of considerable concern for their carers. For at least the 12 months before insertion of a gastrostomy feeding tube there had been inadequate or no weight gain, and concern over their child's poor nutritional status was the main reason for referral to specialist feeding clinics in three hospitals.

After commencement of gastrostomy tube feeding with a proprietary enteral formula, all children gained weight significantly. This weight gain occurred progressively between the measurement points at baseline and 6 and 12 months after insertion of the gastrostomy. As would be expected, weight gain was accompanied by significant increases in limb length and skinfold thickness, indicating the deposition of subcutaneous fat in the various sites examined.

Reassuringly, the gains in *z* score for all growth indices were not dependent on the age of the child. In addition, the change in weight *z* score and in ponderal measurements did not differ significantly between those with available arm and leg length measures and those without. Most of the missing arm and leg data arose from the fact that the reference data started from age 3 years; that is, they were unavoidable and would not be expected to impart a bias.

As has been observed by other workers (Rempel et al. 1988), the effect of nutritional intervention in this study on ponderal growth was significantly more marked than that on linear growth.

Interpretation of the nutritional intake data must take into account both the methodological limitations of the 3-day dietary diary method of assessment and the confounding effect of nasogastric tube feeding. After initial clinical assessment, 35 children had been started on enteral feeds through a nasogastric tube to improve their nutritional state before surgery. Indeed, one child who had a weight-for-age *z* score of 2.05 at baseline had been fed by nasogastric tube for several weeks before insertion of the gastrostomy. However, such patient heterogeneity can be viewed as a strength in a pragmatic study of this type: it adds generalizability to the results and emphasizes that the reasons for gastrostomy insertion were varied.

Moreover, a period of nasogastric tube feeding is commonly employed before insertion of gastrostomy to demonstrate that the patient will tolerate tube feeding and will not vomit. Subgroup analysis revealed that this intervention significantly increased the patient's macronutrient intake at the time of initial measurement. Thus, the nasogastrically fed children had an energy intake of 69% of the estimated average requirement (Department of Health 1991), whereas those fed exclusively by mouth had a daily energy intake of 57% of the estimated average requirement. Adjusting for baseline level, gastrostomy tube feeding led to a significant increase in daily energy (and macronutrient) intake after 6 and 12 months.

One explanation for the significant increases in body weight (Fig. 3) could be that the trajectory of growth for these children was already on a steep climb. To investigate this, we collected body weight data where available before gastrostomy tube placement (Fig. 4). Figure 4 shows clearly that for most of the children this was simply not so, and of course we would expect weight to increase naturally with age.

For 11 children measured before gastrostomy, the median *z* score for weight was –3.8 at 6 months before gastrostomy and –3.5 at 12 months before gastrostomy. The Wilcoxon signed-ranks test indicated that there was no significant change in weight *z* score in the 12 months before gastrostomy tube insertion ($p=0.9$).

Figure 3 shows that for 9 out of 10 children, weight *z* score increased during the 12-month period, and in most cases the upward trajectory seems to be similar (note that a *z* score of 0 indicates the population average for age and sex).

Constipation has been reported in over one-quarter of children with disabilities (Sullivan et al. 2000); inadequate dietary fibre intake is one remediable causative factor in this. Data from the present study suggest that enteral feeds used for tube-feeding children with disabilities should be fibre-enriched. Daily fibre intake was well below the recommended level for children (age in years plus 5g per day; American Academy of Pediatrics 1995) at both initial and subsequent assessments (Table III). The proprietary enteral formula used for gastrostomy feeds was not fibre enriched.

There is a difficulty in finding a valid proxy measure of the overall health of a child with severe and complex disabilities. We chose antibiotic usage and hospital admissions over the year after gastrostomy tube insertion, and showed a significant reduction in the number of admissions to hospital.

Table IV: Complications of gastrostomy tube feeding within one year of gastrostomy placement (reported by carers)

Complication	*Number of children/total (%)*
Minor site infection	27/46 (59)
Granulation tissue	20/48 (42)
Leakage	14/46 (30)
Tube blockages	9/47 (19)
Tube migration	3/46 (7)
Child pulled tube out	2/46 (4)
Peritonitis	1/46 (2)

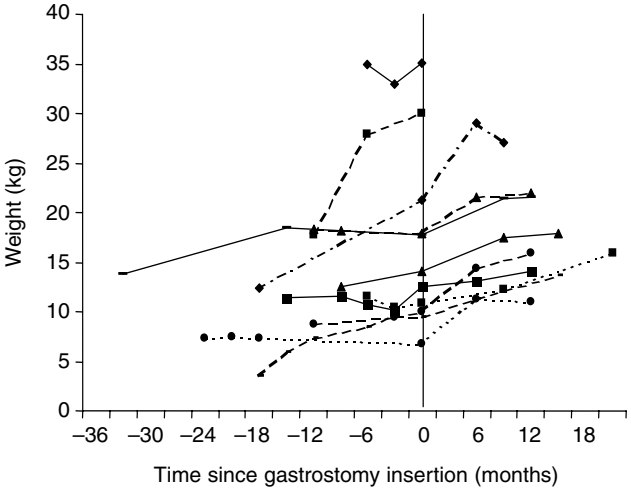

Figure 4: *Body weight over time for all children for whom previous weight was available.*

Although minor complications (gastrostomy site infection and granulation tissue) were common, serious complications after gastrostomy tube insertion were rare, and almost all parents reported that they believed that their child's health had improved significantly since this intervention.

Thus the significant reduction in concern of parents about their child's nutritional status after gastrostomy tube feeding was accompanied by improvements in their perception of the child's health and a significant reduction in time spent feeding. The impact of these changes on carer quality of life was the subject of a companion study (Sullivan et al. 2004).

As has been clearly pointed out by Samson-Fang et al. (2003) in a report for the American Academy of Cerebral Palsy and Developmental Medicine, and in a recent Cochrane review (Sleigh et al. 2004), the published evidence supporting gastrostomy tube feeding as an effective nutritional intervention in children with CP is weak. Most published evidence is merely level V: too confounded by lack of before-and-after documentation for any conclusions to be drawn. The design of the present study addresses these issues both with a full description of the study group (including participant selection and criteria for tube placement) and with detailed assessment before and after the intervention. The existence of some historical data on growth in the year before intervention also adds to the value of the data from the prospective study.

The lack of standardized validated measurements for nutritional intake and for growth in children with neurological disabilities remains a problem for workers in this field. In this study, the data on nutritional intake exemplifies this problem. In addition to the need to establish norms for growth and energy requirements in children with CP, body composition reference standards are also needed. Future studies on the impact of gastrostomy tube feeding should address both precise measurement of nutritional intake and changes in body composition.

Conclusions

In conclusion, this prospective study of gastrostomy feeding in children with neurological disabilities has demonstrated statistically significant and clinically important increases in weight gain, limb growth, and subcutaneous fat deposition, secondary to a modest increase in nutritional intake. Serious complications arising from this procedure were few; in particular, we found no evidence of an increase in respiratory complications after gastrostomy tube feeding. In addition, we found a reduction in admissions to hospital on account of chest infections. Carers also reported positive perceptions about the child's overall growth and state of health.

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References

American Academy of Pediatrics. (1995) A summary of conference recommendations on dietary fiber in childhood. Conference on Dietary Fiber in Childhood, New York, May 24, 1994. American Academy of Pediatrics. *Pediatrics* **96:** 1023–1028.

Bax MCO. (1964) Terminology and classification of cerebral palsy. *Dev Med Child Neurol* **11:** 295–297.

Bender JS, Levison MA. (1991) Complications after percutaneous endoscopic gastrostomy removal. *Surg Laparosc Endosc* **1:** 101–103.

Brant CQ, Stanich P, Ferrari AP Jr. (1999) Improvement of children's nutritional status after enteral feeding by PEG: an interim report. *Gastrointest Endosc* **50:** 183–188.

Coben RM, Weintraub A, Di Marino AJ Jr, Cohen S. (1994) Gastroesophageal reflux during gastrostomy feeding. *Gastroenterol.* **106:** 13–18.

Conover WJ. (1980) *Practical Non-parametric Statistics.* New York: John Wiley & Sons.

Corwin DS, Isaacs JS, Georgeson KE, Bartolucci AA, Cloud HH, Craig CB. (1996) Weight and length increases in children after gastrostomy placement. *J Am Diet Assoc* **96:** 874–879.

Dahl M, Thommessen M, Rasmussen M, Selberg T. (1996) Feeding and nutritional characteristics in children with moderate or severe cerebral palsy. *Acta Paediatr* **85:** 697–701.

Department of Health. (1991) *Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. Report on Health and Social Subjects* No. 41. London: The Stationery Office.

Eyman RK, Grossman HJ, Chaney RH, Call TL. (1990) The life expectancy of profoundly handicapped people with mental retardation. *N Engl J Med* **323:** 584–589.

Freeman JV, Cole TJ, Chinn S, Jones PR, White EM, Preece MA. (1995) Cross sectional stature and weight reference curves for the UK 1990. *Arch Dis Child* **73:** 17–24.

Frisancho AR. (1988) *Anthropometric Standards for the Assessment of Growth and Nutritional Status.* Ann Arbor, MI: Health Products.

Fung EB, Samson-Fang L, Stallings VA, Conaway M, Liptak G, Henderson RC, Worley G, O'Donnell M, Calvert R, Rosenbaum P, Rosenbaum P, Chumlea W, Stevenson RD. (2002) Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *J Am Diet Assoc* **102:** 361–373.

Gauderer MW. (1988) Feeding gastrostomy or feeding gastrostomy plus antireflux procedure? *J Pediatr Gastroenterol Nutr* **7:** 795–796.

Gauderer MW, Stellato TA, Olsen MN, Dokler ML. (1988) Percutaneous endoscopoic gastrostomy in 156 children: indications, technique and complications. *Z Kinderchir* **43** (Suppl: 1)**:** 38–40.

Kastner T. (1992) Association between gastrostomy and death: cause or effect? *Am J Ment Retard* **97:** 351–352.

Kastner T, Criscione T, Walsh K. (1994) The role of tube feeding in the mortality of profoundly disabled people with severe mental retardation. *Arch Pediatr Adolesc Med* **148:** 537–538.

Marin OE, Glassman MS, Schoen BT, Caplan DB. (1994) Safety and efficacy of percutaneous endoscopic gastrostomy in children. *Am J Gastroenterol* **89:** 357–361.

Palisano RJ, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, Raina PS, Galuppi BE. (2000) Validation of a model of gross motor function for children with cerebral palsy. *Phys Ther* **80:** 10–85.

Patrick J, Boland M, Stoski D, Murray GE. (1986) Rapid correction of wasting in children with cerebral palsy. *Dev Med Child Neurol* **28:** 734–739.

Reilly S, Skuse D, Poblete X. (1996) Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *J Pediatr* **129:** 877–882.

Rempel GR, Colwell SO, Nelson RP. (1988) Growth in children with cerebral palsy fed via gastrostomy. *Pediatrics* **82:** 857–862.

Samson-Fang L, Butler C, O'Donnell M. (2003) Effects of gastrostomy feeding in children with cerebral palsy: an AACPDM evidence report. *Dev Med Child Neurol* **45:** 415–426.

Sanders KD, Cox K, Cannon R, Blanchard D, Pitcher J, Papathakis P, Varella L, Maughan R. (1990) Growth response to enteral feeding by children with cerebral palsy. *J Parenter Enteral Nutr* **14:** 23–26.
Sleigh G, Sullivan PB, Thomas AG. (2004) Gastrostomy feeding versus oral feeding alone for children with cerebral palsy (Cochrane Review). In: *The Cochrane Library, Issue 2.* Chichester: John Wiley & Sons.
Spender QW, Cronk CE, Charney EB, Stallings VA. (1989) Assessment of linear growth of children with cerebral palsy: use of alternative measures to height or length. *Dev Med Child Neurol* **31:** 206–214.
Strauss D, Kastner T, Ashwal S, White J. (1997) Tube feeding and mortality in children with severe disabilities and mental retardation. *Pediatrics* **99:** 358–362.
Sullivan PB. (1999) Gastrostomy feeding in the disabled child: when is an antireflux procedure required? *Arch Dis Child* **81:** 463–464.
Sullivan PB, Juszczak E, Lambert B, Rose M, Ford-Adams ME, Johnson A. (2002) The impact of feeding problems on the nutritional intake and growth of children with neurological impairment: the Oxford Feeding Study (II). *Dev Med Child Neurol* **44:** 461–467.
Sullivan PB, Lambert B, Ford-Adams M, Griffiths P, Johnson A. (2000) The prevalence and severity of feeding and nutritional problems in children with neurological impairment: the Oxford Feeding Study. *Dev Med Child Neurol* **42:** 674–680.
Sullivan PB, Juszczak E, Bachlet AME, Thomas AG, Lambert B, Vernon-Roberts A, Grant HW, Eltumi M, Alder N, Jenkinson C. (2004) Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Dev Med Child Neurol* **46:** 796–800.