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ORIGINAL ARTICLE

Gastrostomy feeding in cerebral palsy: a systematic review

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Aims: To determine benefits and risks for gastrostomy or jejunostomy feeding compared with oral feeding for children with cerebral palsy.

Methods: Systematic review. Search strategy: electronic databases—Cochrane Library, Medline, Embase, Cinahl, Lilacs, databases of theses, grey literature. Included: relevant systematic reviews, randomised controlled trials, observational studies, case reports. Excluded: non-systematic reviews and qualitative research. Participants: children with cerebral palsy. Intervention: use of gastrostomy or jejunostomy tube to provide nutrition. Outcome: evaluated outcome measures included death, growth, gastro-oesophageal reflux, other complications, psychosocial aspects, and caregiver wellbeing.

Results: No relevant systematic reviews or randomised controlled trials were found. Two cohort studies, 15 case series, and eight case reports met the inclusion criteria. Eight studies specifically described percutaneous endoscopic gastrostomy as the intervention. Weight gain resulted from gastrostomy feeding in most cases. There was an approximately fourfold increased risk of death reported in one cohort study for the gastrostomy fed children. Many complications were reported, including potential for increased gastro-oesophageal reflux and fluid aspiration into the lungs.

Conclusions: Benefits associated with gastrostomy or jejunostomy feeding are difficult to assess from the available evidence. Risks of gastrostomy, particularly in relation to surgical complications, have been described but the size of the risk could not be quantified. The finding of a higher death rate for children fed by gastrostomy may merely reflect the greater disability of these compared with orally fed children. Lack of available evidence and the substantial risk of bias in observational studies suggests that a well conducted randomised controlled trial of sufficient size will be needed to answer these problems.

Children with cerebral palsy (CP) often have difficulty eating and drinking. These difficulties are due to problems with oro-pharyngeal control^{1–3} and oesophageal motility,^{4–6} related gastro-oesophageal reflux (GOR),^{4, 7} and the high risk of aspiration of food/fluid into the lungs.^{8–10} Among the consequent health problems of these feeding difficulties are undernutrition,^{11–16} oesophagitis with bleeding and pain,¹⁷ recurrent chest infections,⁹ and progressive lung disease.¹⁸ Children most at risk for these problems are those with spastic quadriplegic and dystonic CP.^{19, 20} These categories account for one third of all cases of CP in developed countries.²¹ In other countries this proportion may be higher, for example it was 46% in one report from the Philippines.¹⁵ Assuming a prevalence of CP of 2.5–2.0/1000 live births²¹ we can estimate that around 6000 children in the UK^{22, 23} will have significant feeding related health problems due to CP.

Much of this feeding difficulty can be bypassed by giving nourishment through a gastrostomy (or jejunostomy). The percutaneous endoscopic gastrostomy (PEG) has become widely used.^{24, 25} However for families of children with CP the idea of a feeding tube is often distressing.^{26–29}

The effects of enteral feeding for children with CP, apart from weight gain,³⁰ have not been clearly described. There is controversy about whether gastrostomy feeding may increase the risk of death^{20, 31} or GOR.^{32–35}

Understanding the effects of tube feeding for children with CP is made even more difficult because gastrostomy feeding is also used for children^{36–39} and adults⁴⁰ with a wide range of other conditions both acute and chronic. These include rehabilitation from traumatic head injury⁴¹ or cerebrovascular accidents,⁴² inflammatory bowel disease,⁴³ progressive neurological or metabolic disorders,⁴⁴ cancer,^{45, 46} and AIDS.⁴⁷ Studies of gastrostomy feeding often include a range of ages and underlying conditions. But the type and frequency of outcomes will be influenced by the underlying medical

condition for which tube feeding was prescribed. For example, cancer or AIDS may increase the risk of infection,⁴⁷ children with a progressive disorder may have an increased mortality risk,^{32, 48} and some children recover from their physical disability³² and no longer need their gastrostomy. CP is a non-progressive disorder,⁴⁹ but the neurological problems that result in the feeding difficulty persist. So the relevance, for children with CP, of the findings from studies that include a mixed age range and a variety of diagnoses is unclear.

The management of eating problems for children with CP is difficult and the potential effects of gastrostomy tube feeding on the health of these children is controversial. Families with affected children need better information when making the difficult decision about whether to accept or request a gastrostomy for their child. We therefore undertook a systematic review of the available literature in order to answer the question ‘‘What is the balance of benefits and risks to children with CP from gastrostomy or jejunostomy tube feeding?’’.

METHODS

Inclusion criteria

Types of studies

The review included any systematic reviews, randomised controlled trials (RCTs), whether published or unpublished, and any published observational studies which addressed the effect of gastrostomy feeding for children with eating difficulties due to CP. Neither the language nor country of origin were reasons for exclusion of studies.

Abbreviations: ARP, antireflux procedure; CP, cerebral palsy; GF, gastrostomy fed; GOR, gastro-oesophageal reflux; PEG, percutaneous endoscopic gastrostomy; OR, orally fed; RCT, randomised controlled trial

Qualitative studies, non-systematic reviews, personal practice papers, and annotations were excluded.

Types of participants

Children with cerebral palsy (as defined by the study authors) and feeding difficulties.

Studies that included a majority (greater than 50%) of children with feeding difficulties due to causes other than cerebral palsy or studies that included a majority of adults (over 16 years of age) were excluded.

Types of interventions

Delivery of nutrition via a gastrostomy or jejunostomy tube. Studies in which some children in the intervention group also received some nutrition by mouth, had surgical antireflux procedures performed, or were taking antireflux or other medication were eligible for inclusion. The comparison group were children receiving nutrition solely by mouth.

Studies that had a majority of children who were fed by nasogastric or nasojejunal route either as the intervention or prior to the intervention were excluded.

Types of outcome measures

Death, growth, development, psychosocial effects, and other measures of health, such as complications of surgery, changes in symptoms of GOR and respiratory disease for the child, and measures of physical health and psychosocial effects for their carers.

Search strategy for identification of studies

This included searches in electronic databases (the Cochrane Library, Medline, Cinahl, Latin American and Caribbean Center on Health Sciences Information (Lilacs), ASLIB, and Dissertation Abstracts), hand searching relevant journals, grey literature, and contacting authors and manufacturers who are concerned with gastrostomy feeding to ask if they knew of any relevant unpublished RCTs.

The following search strategy was used in Medline:

- #1 explode "Child-"/all subheadings in MIME,MJME
- #2 infant* or baby or babies or child* or teen*
- #3 young person* or young people or youth or adolescen*
- #4 girl* or boy* or preschool*
- #5 #1 or #2 or #3 or #4
- #6 explode "Enteral-Nutrition"/all topical subheadings in MIME,MJME
- #7 (tube* near feed*) or (enteral near feed*) or (enteral near nutrition)
- #8 gastrostom* or jejunostom* or gastro-jejunostom* or gastrojejunostom*
- #9 #6 or #7 or #8
- #10 explode "Central-Nervous-System-Diseases"/all topical subheadings in MIME,MJME
- #11 explode "Cerebral-Palsy"/all topical subheadings in MIME,MJME
- #12 cerebral palsy or Little* disease or (spastic near diplegia*) or (spastic near quadriplegia*)
- #13 nervous system disorder* or nervous system disease*
- #14 (cerebral near palsy) or (neuro* near disab*) or (neuro* near impair*)
- #15 #10 or #11 or #12 or #13 or #14
- #16 #5 and #9 and #15

The search strategy, with minor modifications as required, was also used in Embase, Cinahl, and the Cochrane Controlled Trials Register. A simpler free text search was used in Lilacs, Aslib, and Dissertation abstracts. The search

histories used in each of the electronic databases are available from the authors on request.

Methods of the review

The titles and abstracts of all studies found through electronic searches were scrutinised by one reviewer (GS). Search for randomised controlled trials was conducted independently by two researchers (GS and JA). Full copies of potentially relevant studies found through the complete search were obtained and, for those that met the inclusion criteria, data were extracted onto a specifically designed form. These studies were assessed independently by the two reviewers (GS and PB). Any disagreement was resolved by discussion. In some cases the author of the paper was contacted for further information. If the data remained unavailable the study was excluded. The reason for exclusion of studies was recorded. Data were summarised in tables. Published guidelines for assessment of study quality⁵⁰⁻⁵⁶ were used.

Analysis

A priori, synthesis of data for this review (meta-analysis) was planned for RCTs only. As meta-analysis of data published in observational studies can only combine crude data, without adjustment for potential confounding factors, it was not considered appropriate to perform any data synthesis for these studies. Where possible adjusted estimates of effect (risk ratios, odds ratios, or hazards ratios) are presented separately for each study.

RESULTS

Results of the literature search

The search in Medline, Embase, and CINAHL retrieved 418 studies. Only seven additional studies were found from the rest of the search strategy. A total of 120 papers that appeared to be relevant were obtained and read. Twenty five studies, two cohort,^{16 31} 15 case series,^{57 19 20 33 58-68} and eight case reports^{18 69-75} met the inclusion criteria and were reviewed. One research project in progress was found.⁷⁶ This was not included in the review. Ninety five papers were excluded. Thirty three of these did not include a majority of children with CP.^{6 44 47 48 77-91 35 92-96 34 97-103} A further seven studies did not specify the number of children with CP. Since it was not possible to obtain the data from the authors they were excluded.¹⁰⁴⁻¹¹⁰ Sixteen studies involved mainly or all adults^{40-42 111-123} and 22 were not research, for example, annotations or reports of personal practice.^{1 24 25 124-142} Sixteen were excluded for other reasons, including use of naso-gastric, or naso-jejunal tube feeds as the intervention,^{30 143} or prior to gastrostomy/jejunostomy;^{32 144-146} surgical procedures;¹⁴⁷⁻¹⁴⁹ and qualitative studies.^{26-29 150 151} For one further study it was not possible to tell the proportion of either adults or children with CP among the gastrostomy fed group.¹⁵²

These 120 potentially relevant studies originated from the following countries: USA, UK, Canada, Australia, New Zealand, Sweden, France, Italy, Spain, Germany, Switzerland, Austria, Brazil, Chile, Taiwan, and Japan.

Characteristics of the studies

All 25 included studies were observational; eight studies reported PEG as the intervention.

No relevant systematic reviews of randomised controlled trials or of observational studies were found and no relevant randomised controlled trials were found.

Tables 1-3 summarise the characteristics and results of the studies according to methodology.

Only two studies had a concurrent control group, both cohort studies (table 1). In the first of these³¹ data were gathered retrospectively from the client development evaluation report.

This report is maintained for each individual who accesses the services for people with developmental disability in the State of California. The study compared the risk of death for the 1060 children with CP who were fed via a gastrostomy feeding tube with the risk of death for children with CP who were orally fed. The orally fed group comprised 5980 children who had at least some self-feeding skills and 5670 children who were totally dependent on someone else to feed them.

The second study¹⁶ involved children already enrolled in the North American Growth in Cerebral Palsy Project (NAGCPP) that includes all known children with CP in several geographically areas in the USA and Canada. All participants in this study¹⁶ were children with moderate or severe motor impairment, scoring III to V on the Gross Motor Function Classification System (GMFCS).¹⁵³ The study's aim was to document, using a simple parental questionnaire, the prevalence of feeding dysfunction in children with moderate to severe physical disability due to CP. Within this study group there was a subgroup of 49 children who were fed by gastrostomy tube. These were compared with a subgroup of 70 orally fed children who scored V, the most severe category, on the GMFCS. These two subgroups comprised the cohort study. Outcome measures for the cohort study comprised administration of the Child Health Questionnaire (CHQ),¹⁵⁴ the NAGCPP questionnaire

(NAGQ)¹⁶ and measures of growth and nutrition that had been recorded already from the NAGCPP.

The 15 case series studies (table 2) describe children with CP, severe physical disability, and associated feeding problems referred to a specialist clinic because of professional concern about poor nourishment. This had resulted in placement of a gastrostomy or jejunostomy feeding tube. One of the studies⁶⁶ described children who in addition to the above characteristics had osteopenia diagnosed radiologically. Many of the children in these 15 studies also had severe learning difficulties and epilepsy. Aspiration and GOR were additional to poor nutrition as indications for gastrostomy or jejunostomy in some studies.^{64 65} Five studies were retrospective, five prospective. Five were mixed retrospective and prospective; these studies used retrospective chart review to identify the children and provide some data, with prospective assessments of, for example, growth,¹⁹ caregiver satisfaction,^{19 20 59} and diet.⁶⁶

Mean reported follow up ranged from 8.4 months to 3.5 years.

A variety of outcomes were assessed in the 15 studies: GOR (10), growth (8), survival (7), major complications (8), other complications (7), caregiver satisfaction (6), nutritional assessment (4) restoration of full oral feeding (2), and other benefits for the child, such as state of alertness and improvement in mood (5).

Table 1 Summary of reviewed studies; cohort

First author and date	Method	Participants	Recruitment period	Intervention and control	Length of follow up	Outcome
Strauss ³¹ 1998	Retrospective survey data from the Client Development Evaluation Report of the service for the State of California.	12 709 children with CP. 1060 were fed by gastrostomy and 11 659 were orally fed. Of these 5980 had some self-feeding skills and 5679 required total assistance with feeding. The referent group for gastrostomy feeding were those with some self-feeding skills. Mean age: not stated. Range: greater than 6 months and less than 3 years 6 months.	1980-95 (all children who had registered with the service during 1980-95).	Gastrostomy feeding versus oral feeding (with some self feeding skills).	Until 1995 (0 to 15 years)	GOR: not reported. Growth: not reported. Death: children with CP who were fed by gastrostomy had a crude hazard ratio* for death of 23.65 compared with children with CP who had some self-feeding skills. When other risk factors (e.g. level of physical disability) were accounted for the relative risk of death was: 5.14 (95% CI 3.89-6.80) gastrostomy placed by 1 year of age, 3.85 (95% CI 2.88-5.14) gastrostomy placed between 2 and 3 years
Fung ¹⁶ 2002	Prospective cohort	119 children with CP and severe gross motor impairment. 49 fed by gastrostomy and 70 orally fed (this is a subgroup of the total group reported). Mean age: not stated. Range: not stated.	Not stated.	Gastrostomy feeding versus oral feeding.	Not stated.	GOR: not reported. Growth: weight, orally fed $z = -2.77$ (sd 2.56), gastrostomy fed $z = -2.15$ (sd 2.19), $p < 0.082$. Triceps skinfold thickness, orally fed $z = -0.94$ (sd 0.99), gastrostomy fed, $z = -0.15$ (sd 1.31) $p < 0.001$. Death: not applicable. Other: The following outcomes were significantly different: CHQ (global health), orally fed $z = 0.46$ (sd 1.24), gastrostomy fed $z = -1.84$ (sd 1.04) $p < 0.001$. CHQ (physical summary), orally fed mean: = 38.1 (sd 15.6), gastrostomy fed mean: = 23.6 (sd 17.3) $p < 0.001$. CHQ (impact on parent, emotion), orally fed $z = -0.07$ (sd 1.20), gastrostomy fed $z = -0.80$ (sd 1.40) $p < 0.004$.

*Hazard ratio presented to take account of varied follow up period (0 to 15 years).
CP, cerebral palsy; GOR, gastro-oesophageal reflux; CHQ, child health questionnaire.¹⁵⁴

Table 2 Summary of reviewed studies; case series

First author and date	Method	Participants	Recruitment period	Intervention	Length of follow up	Outcome
Shapiro ⁵⁷ 1986	Retrospective	19 children with severe disability. 14 with CP. Mean age: 5 years. Range: 5 months–14 years.	Gastrostomy done 1981 onwards.	Gastrostomy, (+ ARP in 5).	Mean: 2 years. Range: 6 months to 41 months. Lost: none.	GOR: 5 had persistent vomiting after gastrostomy. 2 underwent ARP. Growth: weight, increased and 16 increased their weight/length ratio. Death: none. Other: major complications, none reported.
Rempel ¹⁹ 1988	Retrospective and prospective.	57 children with CP. Mean age: 10.7 years. Range: 9 months–23 years.	Gastrostomy, 10 done during 1968–83, rest later.	Gastrostomy, (+ ARP in 24).	Mean: 3.4 years. Range: 3 months to 18.3 years. Lost: 22 did not have pre and post gastrostomy measures of growth.	GOR: 8/33 symptomatic after gastrostomy and underwent ARP. 6/24 underwent further surgery for GOR (4 revision of ARP, 2 feeding jejunostomies). Growth: weight, 24/35 accelerated gain. length, 8/35 accelerated gain. Death: 8 (5 within 1 year of surgery). Other: major complications, 13/57, including gastrointestinal bleeding and ulceration (5), peritonitis (3), other (5). Caregiver satisfaction, ease of feeding, improvement in child's disposition and nutrition were main advantages for the majority. GOR: 5 symptomatic GOR after gastrostomy with ARP.
Sanders ⁵⁸ 1990	Retrospective	51 children with CP. Mean age: not stated. Range: 3 months–15.5 years.	Children referred to clinic during 1980–86.	Gastrostomy in 47 (+ ARP in 44). 4 fed only by nasogastric tube	Mean: 2.4 years. Range: 6 months to 5.5 years. Lost: none	Growth: weight, improved in all but 1. Length, minimal change overall. Death: 7/51. Other: reports of improved alertness and less irritability in some children.
McGrath ⁵⁹ 1992	Retrospective and prospective	61 children with CP. Mean age: not stated. Range: 17 years or less.	Gastrostomy done 1984–89.	Gastrostomy (+ ARP in 57).	Mean: 2.4 years. Range: 1 month to 6.5 years. Lost: 1, 6 months after surgery.	GOR: 9 symptomatic GOR after gastrostomy with ARP. Growth: not reported. Death: 16/60, 14 died within 2 years of gastrostomy (14 respiratory related). Other: 20/60 children had 32 complications within the 1st week after gastrostomy-respiratory (21), other (11). 29 children had 36 late complications including paraoesophageal/hialatal hernias (8), small bowel obstruction (7), retching vomiting and dumping syndrome (15), respiratory (7), wound infection (2). 20 children underwent further surgery, 13 once and 7 twice. Caregiver satisfaction: 53/57 caregivers polled were pleased with the gastrostomy and 55/57 said child's comfort and abilities were enhanced.
Lewis ³³ 1994	Prospective	10 children with CP.	Not stated.	PEG with aggressive enteral feeding regimen.	Mean: 8.4 months.	GOR: 1 underwent ARP for GOR soon after gastrostomy. 3/9 who achieved the nutritional target after gastrostomy got worse GOR when antireflux medication was stopped, 1 underwent ARP. 6 improved and remained off antireflux medication.

Table 2 Continued

First author and date	Method	Participants	Recruitment period	Intervention	Length of follow up	Outcome
		Mean age: 9.1 years. Range: 4–13 years.			Range: 2 months to 10 months. Lost: none.	Growth: weight, 9/10 gained and triceps skinfold thickness reached target (>50th centile for age). Death: not reported. Other: major complications, not reported. GOR: not reported.
Isaacs ⁶⁰ 1994	Retrospective and prospective.	22 children with severe neurological disability. 15 with CP. Mean age: not stated. Range: 2–12 years.	Not stated.	Gastrostomy. ≥ 50% of total energy intake via gastrostomy.	Mean: not stated. Range: 10 months to 4 years. Lost: none.	Growth: weight, 21/22 gained Length, 9/22 gained by first check following gastrostomy (exact timing not stated). Subsequent measures: 11 increased weight z scores Death: not reported. Other: not reported. GOR: 2 children had increased vomiting after PEG (1 new, 1 worse). 7 children had less vomiting. None underwent ARP after PEG insertion. Growth: not reported.
Borowitz ⁶¹ 1997	Prospective	19 children with severe neurological disability. 14 with CP. Mean age: 33.6 months. Range: 1.5 months–13.1 years.	PEG done between 1991–93.	PEG.	Mean: 20.7 months. Range: 7 months to 33 months. Lost: none.	Death: none reported. Other: 2 had more respiratory infections after PEG and 5 had less. Caregiver satisfaction, 17 reported less stress. 19 would recommend PEG to other families. GOR: within 6 months post PEG, 44 had new or worse GOR, 11 of whom had an acute hospital admission (7 with pneumonia). 13 underwent further surgery for GOR Growth: not reported.
Bachrach ⁶² 1998	Retrospective	101 children with severe neurological disability. Mainly CP. Mean age: not stated. Range: 3 months–20 years.	PEG done between 1991–1997.	PEG.	Mean: not stated. Range: not stated. Median: 6 months (all followed for at least 6 months). Lost: none.	Death: none associated with PEG tube placement. Other: technical complications included failure to place PEG (2), gastrocolic fistula (1), tract dehiscence at 1st PEG tube change (4). 9% had site infections. GOR: not reported. Growth: not reported.
Commisso ⁶³ 1998	Retrospective	77 children with CP. Mean age: 5.4 years. Range: <18 years at surgery.	Gastrostomy done between 1992–97.	Gastrostomy. PEG in 32, surgical gastrostomy alone in 20, gastrostomy +ARP in 25.	143.1 person years. Lost: none reported.	Death: 7/77. Other: not reported. GOR: 8 underwent ARP for worsening GOR Growth: weight, increased in 81 children, (z score for weight p<0.001) at 6 and 12 months. Death: none related to procedure, other deaths not stated.
Sulaeman ⁶⁴ 1998	Retrospective	85 children, 79 with neurological disability. 63 with CP. Mean age: 7 years. Range: 1 month–22 years.	PEG done 1990–1995.	PEG.	Mean: not stated. Range: 1 year to 4 years. Lost: none reported.	Growth: weight, increased in 81 children, (z score for weight p<0.001) at 6 and 12 months. Death: none related to procedure, other deaths not stated.

Table 2 Continued

First author and date	Method	Participants	Recruitment period	Intervention	Length of follow up	Outcome
Brant ⁶⁵ 1999	Prospective	20 children with neurological impairment, 16 with CP. Mean age: 6.5 years. Range: 8 months–15 years.	Gastrostomy done 1996–1997.	PEG.	Mean: 5.7 months. Range: 2 months to 10 months. Lost: none reported.	Other: major complications requiring further surgery in 2: separation of the abdominal wall and severe infection with tube migration. 14 children had minor complications, acutely post PEG, wound infection (6), site problems (7), tube migration (1). Longer term complications not reported. GOR: 3 had symptoms of GOR after PEG. Growth: weight, z scores increased after PEG ($p < 0.01$). Length, z scores for length, height/weight ratio, and height/age ratio unchanged. Death: not reported. Other: complications 18, including tube replacement (3), granulations (7), ostomy infection (7), pneumoperitonitis (1). GOR: not reported
Duncan ⁶⁶ 1999	Retrospective	19 children with CP. Mean age: not stated Range: 28 months–18 years.	Not stated.	Gastrostomy. Entire nutrition via gastrostomy with commercially prepared formula and supplements.	Mean: not stated. Range: not stated. Lost: none.	Growth: not reported. Death: not reported. Other: 10 were osteopenic (radiological diagnosis). 5 had fractures without significant trauma. 13 received <50% of recommended caloric intake. Minerals and micronutrients were also deficient compared with recommended daily intake and included calcium, phosphorus, vitamin D, iron, copper, zinc, and magnesium. 18/19 received excess folic acid and vitamin B 12. GOR: 14/27 continued symptoms of GOR after gastrostomy with ARP. Growth: not reported
Smith ²⁰ 1999	Retrospective and prospective.	41 children with CP in the prospective study group. Mean age: 5.0 years. Range: 2 months–18 years.	Gastrostomy or jejunostomy done 1990–98	Gastrostomy or jejunostomy. (+ ARP in 27)	Mean: 3.5 years. Range: 0 to 8 years Lost: 1.	Death: not reported separately for study group. Other: major complications (8) including volvulus, prolapse, bowel obstruction, ulceration, gastrointestinal bleeds and peritonitis; minor (38/40 children affected) problems included diarrhoea and constipation, blocked tube, site infections and leakage. Caregiver satisfaction: 32/40 stated positive impact on family life, child's mood improved (8). 11 had problems with family functioning and stress. GOR: not reported
Sullivan ⁶⁷ 2002	Prospective	Primary caregivers of 50 children with CP.	Not stated.	Gastrostomy	Mean: not stated. Range: not stated. Seen at 6 months and 12 months.	Growth: not reported. Death: not reported.

Table 2 Continued

First author and date	Method	Participants	Recruitment period	Intervention	Length of follow up	Outcome
Sullivan ⁶⁸ 2002	Prospective	55 children with CP. Mean age: 5.7 years. Range not stated.	Not stated.	Gastrostomy	Lost: 23 at 12 months. Mean: not stated. Range: not stated. Seen at 6 months and 12 months. Lost: not stated.	Other: scores on SF 36 (version II) showed improvement in all domains at 12 months post gastrostomy. The social function score was lower at 6 months than before gastrostomy but higher at 12 months. No tests of significance given. GOR: not reported. Growth: weight, increased over 12 months, mean:33%, range: 6.5–80% body fat, increase in 1st. 6 months mean: 4% (95% CI = 1.4–6.5) p=0.004. Death: not reported. Other: complications not reported nutrition, increase in mean intake of energy (p=0.05) general health, apparently fewer chest infections and fewer hospital admissions for chest infections. Growth: weight, increased over 12 months, mean: 33%, range: 6.5–80% body fat, increase in 1st. 6 months mean:4% (95% CI = 1.4–6.5) p=0.004. Death: not reported. Other: complications not reported nutrition, increase in mean intake of energy (p=0.05) general health, apparently fewer chest infections and fewer hospital admissions for chest infections.

CP, cerebral palsy; GOR, gastro-oesophageal reflux; PEG, percutaneous endoscopic gastrostomy; ARP, antireflux procedure; usually Nissen fundoplication.

However, authors tended to use different criteria to assess the same outcomes. For example, deaths and medical complications were only counted as complications of the gastrostomy if they occurred in the early postoperative period in two studies,^{62 64} while other studies counted complications that occurred throughout the follow up period (the length of which differed between studies); and presence of GOR was variously assessed by radiology,^{19 57 61} 24 hour pH monitoring,^{33 62 64} and oesophagitis diagnosed histologically.^{61 62} In four studies the method was not stated. Caregiver satisfaction was mainly assessed by questionnaires that had been devised by the authors for the study. Only one study⁶⁷ used prospective completion of the questionnaires pre-gastrostomy and at follow up. The development and piloting of the questionnaire for this study had been described previously.¹⁴ However assessment for validity, reliability, appropriateness, and acceptability were not reported for any of the author designed questionnaires in the reviewed studies.

The case reports (table 3) describe children with CP, all of whom had severe physical disability and were fed via a gastrostomy feeding tube. Six of the eight reports are about complications.

Thus the included studies showed considerable heterogeneity in study design that included different methods of recruitment, outcomes assessed, criteria for the inclusion of the outcomes, tools used to assess similar outcomes, and length of follow up. The studies were open to systematic and random bias, only two had a control group.

Findings of the included studies

Findings are summarised in tables 1–3 individually for all included studies.

The first of the two cohort studies³¹ suggests that type of feeding has a major impact on survival. When children with CP fed by gastrostomy tube were compared with orally fed children who had at least some self-feeding skills the hazard ratio was 23.65. However when other factors, such as level of physical disability were held constant the hazard ratio reduced considerably (3.85, 95% CI 2.88 to 5.14) when the gastrostomy was placed between 2 and 3 years of age.

The second cohort study¹⁶ found similarities and differences between the gastrostomy (GF) and orally fed (OF) groups. There was no significant difference in functional communication, nor in hospital stays nor time in bed and school missed due to illness nor in measures of arm muscle mass. Gastrostomy fed children scored worse than controls on the global health z score (OF mean = -0.46 (SD 1.24), GF mean = -1.84 (SD 1.04), p<0.001) and physical summary z score (OF mean = 38.1 (SD 15.6), GF mean = 23.6 (SD 17.3), p<0.001) of the CHQ; they were more likely to be incontinent (OF 47/70 and GF 46/49 children, p<0.001) and families of gastrostomy fed children reported (CHQ) a greater impact on their time (z score OF mean = -0.91 (SD 1.80), GF mean = -1.38 (SD 1.70), p=0.1) and greater emotional impact, which meant more worry about their child's general health (z score OF mean = -0.07 (SD 1.20), GF mean = -0.80 (SD 1.40), p=0.004). However, gastrostomy fed children were reported to have less respiratory illness during the previous year (54/70 and 28/49 children, p=0.03). Growth measures, weight z score (OF mean = -2.77 (SD 2.56), GF mean = -2.15 (SD 2.19), p=0.082), height z score (OF mean = -3.20 (SD 1.63), GF -2.55 (SD 1.26), p=0.014) and triceps skinfold thickness z score (OF mean

Table 3 Summary of included studies; case reports

First author and date	Participants	Intervention	Length of follow up	Outcome	Author's comment
Kirberg ⁶⁹ 1988	2 children with CP, feeding difficulty and aspiration. Ages: 3 and 16 months.	PEG.	7 and 4 months respectively.	GOR: none. Growth: not reported. Death: none. Complications: immediate none, no site infection.	Safe quick procedure took only 7–8 minutes.
Langley ⁷⁰ 1995	1 child with CP and feeding difficulty. Age 18 months.	Gastrostomy, then a user friendly behavioural programme with aim of reinstating oral feeding.	10 months.	GOR: not reported. Growth: not reported. Death: no. Other: All nutrition taken by mouth 10 months after start of behavioural programme.	There were psychosocial, as well as physical components, to the eating difficulty.
Patel ⁷¹ 1997	1 child with CP and symptomatic GOR. Age 2 years.	Gastrostomy and ARP.	12 months.	GOR: not reported. Growth: not reported. Death: no. Other: major complication, 3 weeks after gastrostomy underwent emergency investigation and surgery for volvulus of the stomach between the oesophagus and the gastrostomy.	Child made good recovery following the 2nd operation, no further episodes of volvulus occurred during 12 months follow up.
Rashid ¹⁸ 1997	1 child with CP, feeding difficulty and aspiration. Age: 2.5 years.	Gastrostomy and ARP	15 months.	GOR: not reported after gastrostomy and ARP. Growth: slightly overweight. Death: yes. Other: major complication, acute pancreatitis, confirmed at autopsy as the cause of death. Lungs showed evidence of old aspiration pneumonia.	Hypothesis: regurgitation of pancreatic juices causes pancreatitis and may occur due to intermittent obstruction of the duodenum or ampulla of Vater by the tube.
Worley ⁷² 1998	1 child with CP and feeding difficulty. Age: 9 years.	Gastrostomy and refeeding.	Not stated.	GOR: not reported. Growth: weight, average for 15.5 month old. Length, average for 31 month old. Death: no. Other: complication, poor nourishment due to failure to feed adequately. On re-feeding in hospital developed asymptomatic hypophosphataemia.	Parents were poor and had not realised that the gastrostomy feeds could be obtained from a government assistance programme.
Clancy ⁷³ 2000	1 child with CP and feeding difficulty. Age: 7 years. 1 child with CP and feeding difficulty. Age: 7 years.	PEG.	Not stated.	GOR: not reported. Growth: not reported. Death: not reported. Other: complication, acute intestinal obstruction, feeding tube wedged in 1st part of duodenum.	Feeding tube removed by gastroscope, new tube inserted, feeding commenced within 4 hours.
Tedeschi ⁷⁴ 2000	1 child with CP, feeding difficulty and respiratory crises during meals.	Gastrostomy	18 months	GOR: respiratory crises did not improve with gastrostomy.	Infants with feeding problems and CP may show maturation in feeding patterns. The author considered the gastrostomy to be unhelpful and the infection to have caused "indescribable suffering".

Table 3 Continued

First author and date	Participants	Intervention	Length of follow up	Outcome	Author's comment
	Age: 16 months.			Improvement occurred with maturity and antacid and prokinetic medication. Growth: not reported. Death: no. Other: Severe fungal infection at ostomy site. By 3 years able to self feed orally with aids. GOR: not reported after ARP.	
Jones ⁷⁵ 2001	1 child with CP and GOR with persistent vomiting treated unsuccessfully with dietary manipulation. Age: 3 years.	Gastrostomy and ARP.	9 months.	Growth: weight, on 50th centile when admitted to hospital. Death: no Other: complication, clinical signs of scurvy, multiple fractures with demineralisation of bones, and peripheral oedema. Tests confirmed vitamin C (severe), vitamin A and zinc deficiency.	Within 1 month of supplements clinical symptoms and signs of scurvy had gone and bony callous formed.

Key: ARP, antireflux procedure; CP, cerebral palsy; GOR, gastro-oesophageal reflux; PEG, percutaneous endoscopic gastrostomy

-0.94 (SD 0.99), GF mean = -0.15 (SD 1.31), $p = 0.001$), all favoured the gastrostomy fed children.

For the case series (table 2), GOR was most the most frequently reported outcome. All 10 of the case series studies that assessed GOR^{19 20 33 57-59 61 62 64 65} reported that one or more children had new, continued, or worse GOR following gastrostomy tube feeding. Sometimes this occurred in spite of a surgical antireflux procedure (ARP) concurrent with the gastrostomy.^{19 20 58 59} Most children's symptoms improved when treated with antacids and prokinetic medication, but in seven of the studies some children underwent new or further ARPs because of continuing severe symptoms of GOR. Two studies suggested improvement in GOR following PEG. In one⁶¹ 7/14 children had less vomiting but, although in two GOR was worse, neither underwent an ARP. The second study³³ reported that 6/10 children improved and remained off antireflux medication during the follow up period of 8-18 months. However four of the 10 could not be weaned off the antireflux medication and two of these underwent ARPs. In spite of this the author's conclusion was that "nutritional rehabilitation resulted in marked improvement of GER in these patients".³³

All eight studies that assessed growth^{19 33 57 58 60 64 65 68} found that most, though not all, children showed improved

weight gain after gastrostomy tube feeding. Change in rate of length growth, reported in four studies,^{19 57 58 65} appeared to be less predictable and occurred only in a minority of children.

Of the seven case series reporting death,^{19 58 59 62-65} no deaths occurred in two studies.^{62 64} The lack of a control group, varying length of follow up, and varying numbers of study participants makes it impossible to gain any impression of the risk of death posed by gastrostomy feeding.

Table 4 lists the other major complications that were reported in relation to gastrostomy or jejunostomy tube feeding in the reviewed studies. This table is derived from the studies in tables 2 and 3 and, as there is no clear denominator, the incidence of these complications cannot be estimated. The complications involve issues about the surgical technique, the intra-abdominal equipment, and the artificial "feeds" that are used to provide nourishment. Relatively minor complications are frequently mentioned in the case series (table 2) and included site infections, granulations, leakage round the tube, tube migration, pneumoperitoneum, blocked tube, vomiting, retching, dumping syndrome, diarrhoea, and constipation. The proportion of children affected by these minor complications can be as high as 95%.²⁰ Most of the caregivers polled in the case series appeared satisfied with the gastrostomy for their child.^{19 20 59 61} Benefits included: ease of feeding; improvement in child's disposition and nutrition;¹⁹ 53/57 were pleased with the gastrostomy and child's comfort and abilities enhanced;⁵⁹ 17/19 reported less stress; and 19 would recommend PEG to other families.⁶¹ In one study²⁰ 32/40 believed gastrostomy had a positive impact on the life of their child and the rest of the family. However, 11 of these 40 found problems with family functioning and stress. Problems with family functioning and stress included difficulty getting respite care because of lack of adequately trained caregivers, restriction of mobility especially if a pump was used, finding a changed relationship with their child, and their child missing the taste of food. Restoration of total oral feeding as an outcome was the subject of two case reports^{70 74} (table 3); it was mentioned in only two of the case series. In one of these⁵⁹ four children were being fully orally fed at follow up, but in the other³⁸ both patients had died following resumption of full oral feeding.

Although the inclusion criteria for this review were specific, it was not possible to draw firm conclusions about the risks and benefits of gastrostomy tube feeding for

Table 4 Major complications reported related to gastrostomy or jejunostomy feeding tube placement for children with cerebral palsy

Failure to place the tube
Acute postoperative respiratory problems
Wound dehiscence
Severe wound and abdominal wall infection
Further surgery for: failure of initial operation, for antireflux procedure, treatment of surgical complications
Gastrointestinal bleeding/ulceration
Paraoesophageal/hiatus hernia
Peritonitis
Acute intestinal obstruction due to tube migration or dislodgement of parts of the feeding tube system
Gastrocolic fistula
Tract dehiscence
Volvulus
Acute pancreatitis
Chronic respiratory problems, often related to aspiration into the lungs
Osteopenia and bone fractures
Scurvy and other mineral and micronutrient deficiencies

children with cerebral palsy because of the severe methodological weaknesses of most of the included studies.

DISCUSSION

The results of this review show that gastrostomy feeding for children with physical difficulty eating due to cerebral palsy is practiced in many countries. There is a general assumption that it is a necessary, safe, and effective treatment.^{61–64} However, this review suggests that there is no firm evidence for this assumption and the outcomes for the two cohort studies appear less in favour of gastrostomy than conclusions drawn from the case series studies.

The main weakness of both cohort studies is that the control group children were unlikely to have been as severely disabled as the gastrostomy group. In the first, gastrostomy fed children were compared with orally fed children who had “some self-feeding skills” rather than those who were “fed by others, no feed tube”.³¹ The children with some self-feeding skills are likely to be the least disabled of these three groups and those with gastrostomy the most disabled. This may explain the excess of deaths in the gastrostomy group. This explanation is supported by the finding³¹ (table 1) that the association between feeding and death was substantially reduced when other confounding factors were controlled for. This raises the possibility that this adjusted relation is still biased by residual or uncontrolled confounding. This study also found a strong correlation between survival time and degree of physical disability. For example, 50% of gastrostomy fed children with CP unable to lift their heads in prone lying survived beyond the age of 7 years. But this was extended to 50% survival beyond 12 years of age if they could lift their heads. This suggests that quite a subtle difference in motor control has a major impact on additional years survived.

In the second cohort study, the investigators chose the control group from those orally fed children who were most severely disabled (GMFCS V). However, within category V there are gradations of disability.¹⁵³ For instance both categories of head control mentioned above,³¹ that had markedly different survival outcomes, would be included in category V. Moreover this study¹⁶ found that the tube fed children were significantly more likely to be incontinent than their orally fed controls. The gastrostomy fed children then, may have been more severely disabled and/or had poorer general health than the orally fed children. If this was the case it could explain why the scores for global health and physical summary domains were worse for the gastrostomy fed children than controls, and why parents of gastrostomy fed children had more worries about their child’s health.

These concerns about confounding mean that neither of the cohort studies answers the crucial question as to whether the apparently less favourable aspects for the gastrostomy fed children are due to the gastrostomy tube feeding or to the child’s disability and general health.

Aspiration of food or fluid into the lungs is almost certainly a major risk factor for ill health⁹ and thus decreased length of survival in children with CP; respiratory problems are not infrequently mentioned as the cause of death.^{20–32–155}

Direct aspiration of orally ingested material and saliva may be a reason for recommending gastrostomy tube feeding.^{64–65} But GOR is also thought to contribute to aspiration indirectly; for example, refluxed gastric juices were seen to reach the pharynx during videofluoroscopy.⁹ It is important then to know whether gastrostomy tube feeding for children with CP results in new or worse GOR. As has been shown this review did not allow any firm conclusion to be drawn about whether GOR was increased or decreased with gastrostomy tube feeding.

Because most symptomatic children respond to prokinetic and antacid medication, and ARPs are not always successful for children with CP,⁵⁹ most surgeons do not advise routine ARP concurrent with gastrostomy unless a child’s symptoms are severe despite appropriate medication.^{95–156} But both GOR and aspiration can occur without obvious symptoms (silent)⁸ and the investigations that are often used to diagnose GOR appear to be unreliable predictors, in children with CP, so that GOR will become worse after gastrostomy tube feeding.^{32–61–95–105–156} From this review then, regarding GOR, several issues remain unsolved. These include: not understanding the relative contributions of direct and indirect aspiration to chronic lung disease in children with CP; not having reliable ways of diagnosing GOR and aspiration in children with CP; not being able to predict whether and to what extent gastrostomy tube feeding is likely to significantly increase GOR (silent or symptomatic) and, therefore, being unable to predict for individual children whether gastrostomy tube feeding is likely itself to cause lung damage.

Most children with CP appear to get fatter as a result of enteral tube feeding as evidenced by increased weight, triceps skinfold thickness, and altered body fat composition (table 2^{19–33–58–60–64–65–68} and table 1¹⁶). The weight gain reported for most children with CP who receive enteral feeds has advantages, such as looking healthier and feeling warmer, but also disadvantages, such as being more awkward to lift and requiring larger and more obtrusive equipment at home.²⁹

From the review it was not possible to tell whether the children’s overall health or survival was better or worse than it would have been with oral feeding alone, because the majority of studies did not have a control group. Many of the minor complications are unpleasant for the children and/or their carers and may significantly affect their quality of life.⁷⁴

There are also concerns about replacing ordinary food with commercially prepared “feeds”. Dietary balance may be more easily disrupted,^{66–72–75–120} giving rise to micronutrient and vitamin deficiencies,^{66–75–120} and problems with refeeding may occur⁷² if, for some reason, too little feed is given.

The potential negative consequences of gastrostomy feeding are especially important for children with CP since for them tube feeding tends to be a long term solution for their feeding difficulties. Few instances of successful reintroduction of all nutrition by mouth have been reported for this group; it requires skill and patience.^{70–124} Generally the gastrostomy tube can be removed without complication but gastrocutaneous fistula may result and require operative closure.^{81–87} In spite of the reported adverse effects caregiver satisfaction tended to be high; this may simply reflect the likely high level of bias for these findings.

A weakness of this systematic review is that only one author did the search for observational studies; some could have been missed. It is very unlikely that relevant RCTs or systematic reviews were missed, since two researchers searched independently and none of the authors we contacted knew of any published or unpublished RCTs.

CONCLUSION

This systematic review has shown that there is little robust evidence about the effect of gastrostomy (or jejunostomy) tube feeding for children with eating difficulty due to CP. Moreover, serious issues are raised about a potential increased risk of death, the necessity for further surgical procedures, and some life threatening complications. In addition there is some evidence that gastrostomy feeding has a negative impact for families. It is not possible from this systematic review to draw any firm conclusions about whether placing a gastrostomy or jejunostomy for children with CP who have difficulty eating and drinking gives overall

benefit or harm. These issues could be settled by carrying out a well conducted randomised controlled trial of sufficient size to address some of these important outcomes. For example, the sample size required to exclude a doubling of the risk of death with gastrostomy feeding,³¹ assuming that over a five year period 10% of the orally fed children will die, would be 438 children (with 80% power and 95% confidence). For outcomes such as GOR or quality of life measure, substantially fewer children would need to be recruited.

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