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Cost effectiveness of gastrostomy placement for children with neuro-developmental disability

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Abstract

Malnutrition and growth deficiency are common in neurologically impaired children. Gastrostomy placement has been shown to result in significant catch up growth, improved health of the child and reduction in family stress; its cost effectiveness has not been investigated. Costs related to gastrostomy placement are estimated here from a prospective controlled study of children referred to a tertiary paediatric centre in UK. Costs of inpatient stay, medication, tests, general practitioner consultations, community health care, equipment, and parents' indirect costs, were estimated at baseline and follow up. Costs of the different types of gastrostomy surgery are given. Results for both time periods were available for 54 of the 76 children recruited to the study. Five day food diaries were kept at baseline and follow up. Costs of food increased slightly but not significantly post surgery from £33 to £40 [44 to 54 euro, 65 to 78 US\$] per week. Variation in cost between cases was considerable but the mean net cost difference of £20.80 (CI -£43.79 to £85.35) [28 euro (CI -59 to 115euro), 41 US\$ (CI -86 to 167US\$)] per week per child including for food and surgery, was also not significant. Community service costs were significantly lower post surgery. Few parents reported personal costs at either time point, although many had reduced or stopped paid work to care for the child. As gastrostomy placement for these children resulted in significant clinical benefit at no significant extra cost, it is concluded that the procedure is cost effective.

Background

Malnutrition and growth deficiency are common in neurologically impaired children considered for gastrostomy. They are likely to be significantly underweight for age, totally dependent on care givers for daily existence¹ and have high requirements for health service resources². A recent paper³ reported that two thirds of the children studied for the medical and psychosocial effects of gastrostomy feeding, achieved significant catch up growth (weight for age, mean gain 0.51 standard deviation score (SDS), CI 0.23 – 0.79, $p < 0.001$ and mid-arm circumference, mean gain 1.12 cms, CI 0.05 to 1.75, $p = 0.001$) and a reduction in drooling, vomiting and constipation. The pre surgery mean weight was -2.84 SDS (range -9.8 to 3.4) and the major nutritional deficit pre was in energy intake; only 7% (4/59) achieved 100% average requirements. Costs are an important element of policy decisions but there have been no estimates of costs of gastrostomy placement in children, although it has been suggested that there may be significant increases in costs when changing to gastrostomy⁴ feeding. This paper attempts to fill this gap, by presenting estimates of costs to health and social services and to families, of the surgery and subsequent cost changes for care and food for the children in this clinical study³.

Methods

Participants were the population of children attending surgical and neurodisability outpatient dysphagia clinics at Great Ormond Street Hospital between 1999 and 2001³. The characteristics of the main sample are described elsewhere³. All had neurological impairment and were recommended for gastrostomy placement with or without antireflux procedure. A self administered economic questionnaire was given to families at recruitment and at six months post surgery, requesting information about use of services and other resource costs during the previous three months. The requested information included; hospital inpatient stay, outpatient or day visits, tests and referrals; consultations with general practitioners including whether home visits; appointments with community professionals (health visitors, speech therapists, occupational therapists, dietitians); equipment provided and bought; medication; parents' expenditure on health care and other costs including days off work, or inability to carry out regular activities due to the child's ill-health. Families were invited to comment on related issues.

Each resource use element was costed for the three month periods, and follow up costs compared with those pre-surgery at baseline; baseline costs represented a control for each child's costs at follow up, so data were included only if questionnaires were returned for both time periods. Mean cost differences, standard errors and 95% confidence intervals were estimated based on cost differences for each individual child. Considerable effort was made to ensure questionnaires were returned and completed; the researcher contacted families for missing questionnaires and data. Where data were still missing within a questionnaire, they were replaced by the mean for the group

Surgical procedures, consultations, tests and hospital stay, were costed using unit costs provided by the finance department of the hospital. General practitioner surgery and home visits, and all other community service use, were costed using published unit costs of social care⁵, medication using the

British National Formulary,⁶ equipment from manufacturers' price lists. Details of surgical procedures were obtained from the surgical outcomes proformas for the clinical study³.

All respondents were requested to keep food diaries for five days at baseline and six months follow up. Diaries for 19 children with complete information at both periods provided the data for calculation of detailed costs of food to families and the NHS. Food purchased by parents was costed using a home shopping website (Tesco.com, March 2002), and the formula feeds using the British National Formulary (bnf.com 2002)⁶. Costs of food were also calculated separately for children fed naso gastrically and orally prior to surgery.

Costs differences between baseline and six month follow up were estimated for each child for each area of cost and for total costs, and the mean differences estimated and tested using paired sample t tests.

The National Institute of Clinical Excellence (NICE) assumes a procedure to be cost effective if it saves a quality adjusted life year at a cost below some £25 000 to £30 000. The benefits of the clinical study were positive, but we were not able to translate these into quality adjusted life years. However, given the clear positive clinical effectiveness, should there also be no significant cost increase, the procedure would be considered highly cost effective by NICE.

Ethical approval was obtained from the Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust research ethics committees and the study discussed with parents following recommendation for gastrostomy. Written consent was obtained at their next appointment.

Results

Ninety two families whose children were offered and accepted gastrostomy during the recruitment period of the study, and who met the study inclusion criteria³, were invited to participate in the study. One child died before consent was obtained; fifteen families declined to participate. The remaining 76 children took part in the clinical study. All were asked to complete economic questionnaires; 54 (71.1%) completed these at both recruitment and follow up and were entered into the economic assessment. The mean age at surgery was 4.45 years (sd 4.2) which was not significantly different from the ages of the main clinical trial; 31 (57%) were male. Categories of disability included 22 (41%) with cerebral palsy, 17 (31.5%) with syndrome of chromosomal or other genetic origin, 9 (17%) with slowly progressive degenerative disease and six (11%) with unconfirmed diagnosis. Just under a half (26/54, 48.1%) had gastrostomy with antireflux procedure; the rest had gastrostomy only. Prior to surgery 33/54 (61.1%) were fed by naso-gastric tube. Statistical analyses revealed no difference between the costed sub-sample and main clinical sample with respect to age, calorific intake, diagnosis and surgery, but the sub sample had higher weight for age than the main study children.

Results are reported for these 54 children and the 19 for whom there were completed food diaries at both baseline and follow up. Mean weekly costs per child for health and social care are given in Table 1. The mean baseline cost was £90, including £39 for inpatient care, £23 for hospital day and outpatient care, and £28 for community service care, of which £8 was for physiotherapy. The mean

follow up cost was £95, with the higher cost due mainly to costs of readmissions for complications of the surgery. The difference of £5 (CI -£31 to £41) is not statistically significant. Community service costs were lower by £8 ($p < 0.05$, CI £1 to £15) including a significant reduction in general practitioner care of £3 (£0 to £5, $p < 0.05$). (Table 1) General practitioner visits fell from a three month mean of 1.8 at baseline to 1.2 at follow up with a mean reduction in home visits of 0.5 (0 to 1.0 $p < 0.05$) (Table 2). Costs of inpatient stay for the main surgery are presented separately in Table 3 together with costs of surgery.

Table 1

Mean weekly costs to Health and Social Services per child in the three months prior to baseline and to follow up (2002 prices)

	Baseline N= 54	Follow up N=54	Cost difference (95% CI) at follow up(N=54))
Hospital services			
Inpatient stay ^a	£39	£57	£18 (-£19 to £56)
Daycare/outpatient	£23	£19	-£4 (-£14 to £5)
Community services			
Physiotherapy	£8	£5	-£3 (-£8 to £1)
GP visits ^b	£5	£2	-£3 (-£5 to £0)*
Speech therapy	£3	£2	-£1 (-£3 to £1)
Paediatric community nurse	£2	£4	£2 (-£1 to £4)
Other community	£9	£7	-£2 (-£9 to £3)
Total community	£28	£19	-£8 (-£15 to -£1)**
Total	£90	£95	£5 (-£30 to £40)

^a excludes stay for gastrostomy

^b includes surgery and home visits

* differences significant at 5% level ** differences significant at 1% level

NB Confidence intervals are based on the standard errors of the mean differences for individual children

Table 2

Mean Number of General practitioner visits per child in previous three months (N=54)

	Baseline	Follow up	Difference (CI)
Surgery visits	1.2	1.1	-0.1 (-0.7 to 0.5)
Home visits	0.6	0.1	-0.5 (-1.0 to 0)*
Total	1.8	1.2	-0.6 (-1.4 to 0.2)

- difference significant $p < 0.05$

Some families were permitted direct access to the hospital for their child post surgery, and comments from parents indicated why hospital services were often used in preference to general practitioner services. For example: *'because he usually fits I usually take him into hospital when he is unwell' 'The GP won't see him'*

But also, *'Through the winter months my GP has called in every two to three weeks to monitor his progress.'*

Pharmaceutical costs

Mean weekly pharmaceutical costs per child over the three month periods were £8.31 at baseline and £7.23 at follow up. This reduction of £1.08 (CI -£1.62 to £3.77) was not significant at the 5% level.

Surgery

Mean costs are given for percutaneous endoscopic gastrostomy (PEG), and antireflux procedure (laparoscopic and abdominal Nissen's). Individual costs of surgery and the related hospital stay and diagnostic test costs, vary considerably with the complexity of the procedure. The Nissen's procedure cost between two and two and a half times the cost of the PEG (Table 3).

Table 3 Mean costs of surgical procedures per child

	Surgery	Hospital stay	Gastrostomy tubes	Tests	Total
Gastrostomy (PEG) (N=41)	£514	£1254			£1778
Laparotomy Nissen's (N=13)	£1543	£2279			£3822
Abdominal Nissen's (N=21)	£1029	£3128			£4257
ALL SURGERY (N=75)	£837	£1956	£53	£132	£2978 (£2626 to £3330)

The benefits of this surgery are long term and usually for life; in the opinion of the surgical team at London's Great Ormond Street Hospital for Children who have extensive specialist knowledge, this would be for at least ten years, which has been used as a conservative figure for spreading the costs of surgery in Table 5 using a discount rate of 6%. The gastrostomy is then estimated to cost £500 per year or £9.66 (£8.52-£10.80) per child per week.

Food

Food is costed at 2002 prices and presented as weekly costs per child in Table 4. There was an increase in the costs of NHS prescribed supplements from £28.87 to £35.37 and a reduction in mean cost of family bought food from £5.99 to £4.58. For children who had naso gastric feeding prior to gastrostomy, the mean weekly food costs to the NHS increased by £9.24 and by £0.48 to the family. This compared with a mean increase of £2.72 to the NHS and a mean decrease to families of £2.76 for children who were orally fed prior to gastrostomy. Neither these nor the overall food cost difference of £4.09 (-£4.36 to £12.57) were statistically significant or substantial.

Table 4

Mean weekly food costs per child at baseline and follow up, mean differences and 95% confidence intervals, 2002 prices (CI based on standard errors of the mean differences for individual children)

Costs of food N=19	Mean £	Mean diff from pre surgery	Lower CI 95%	Upper CI 95%	t	p	df
NHS pre surgery	£28.87						
NHS post surgery	£35.37	£6.50	-£6.12	£19.11	1.09	.337	18
Parent pre surgery	£5.99						
Parent post surgery	£4.58	-£1.41	-£3.95	£1.09	1.18	.290	18

Overall cost differences

The mean total difference in costs including for food and surgery (Table 5) was not significant at £20.78 with 95% confidence interval spanning a cost reduction of £43.79 to a cost increase of £85.35 (approximately £127 per week at baseline, and £148 per week at follow up). Costs for community and hospital day care, pharmaceuticals and disposables (excluding surgery, food and hospital stay) reduced by £13.54 (£3.94 to £23.13) per week, significant at the 1% level (£59.62 at baseline and £46.08 at follow up).

Hospitalisation for complications due to initial surgery occur⁷ (Khattak et al, 1998) and some costs of hospital inpatient stay at follow up may be due to complications, so hospital costs are presented separately in Table 5.

The benefits of surgery are long term and usually for life; in the opinion of the surgical team at London's Great Ormond Street Hospital for Children who have extensive specialist knowledge, this would be for at least ten years, which has been used as a conservative figure for spreading the costs of surgery in Table 5 using a discount rate of 6%. The gastrostomy is then estimated to cost £500 per year or £9.66 (£8.52-£10.80) per child per week.

Table 5 Summary of all mean costs to health and social services per child per week (2002 prices)

Weekly costs per child N=54	Baseline	Follow up	Mean difference (95% CI)
Community services, hospital day/out patient care, pharmaceuticals, and disposables	£59.62	£46.08	-£13.54 (-£23.13 to -£3.94)**
Inpatient stay	£38.69	£56.85	£18.16 (-£19.55 to £55.87)
Food costs (NHS only)	£28.87	£35.37	£6.50 (-£6.12 to £19.11)
Gastrostomy cost	nil	£9.23	£9.23 (£8.14 to £10.32)
All costs	£127.18	£147.96	£20.78(-£43.79 to £85.35)

** significant $p < 0.01$

CI based on standard errors of the mean differences for individual children

Personal Costs

Most carers reported no personal expenditures. Some carers reported minor expenditures or larger costs including for travel and lost earnings. Cost of care of severely disabled children is known to be high^{8 9} and the costs here are undoubtedly under-reported. The mean private expenditure given for

the 54 children is a mean of £7 per week at baseline and £4 at follow up. There is no evidence of significant difference between the two time periods.

Time off work

Due to the very high care requirements of the children, mothers mostly could not work, and there was also frequent report of fathers or partners changing their work to part time or flexible working to accommodate the child's care needs. Comments included:

I don't work. How can I?

Father works nights to care for daughter, but would prefer to work days

My time is taken up every day since he was born. I have to do everything for him

My partner lost five weeks work (in previous three months)

Father has given up full-time work to be more flexible

Father has changed jobs to facilitate appointments. Now has flexible employer

Son had one week off school to care

Again most carers did not report the implications of care on their family's employment and time. The mean time reported (eight days at baseline and five days at follow up with wide confidence intervals) is undoubtedly greatly understated but with no suggestion of statistically significant difference between the time periods.

Discussion

Several studies have reported significant improvement in weight^{3 10 11 12}, reduction in feeding time^{3 4}¹⁰ and stress, and improvement in social functioning^{3 4 10 13} following gastrostomy. The significant clinical benefits of our study have already been reported³. Another study, following children for a mean of 5.6 years (1-10 years) after gastrostomy, reported that 94% of parents said the surgery had a positive influence and 98% would choose it again. It concluded that gastrostomy is a safe technique even for very sick children, that major complications were rare and parents reported it to be of great help to themselves and the child.¹⁴ A further study of 29 caregivers, reported that only one family regretted deciding on the operation¹¹. Costs and savings need to be considered together with these reports of significant health and quality of life benefits and overall parental satisfaction.

Attempts at costing have been few. One other study¹⁵ compared costs of gastrostomy feeding with costs of naso-gastric feeding for 34 adults with cancer. They report, for this very different population, a slightly higher cost for gastrostomy patients of some 6% (by 22.78 Deutsche Marks), but conclude that from an economic point of view, PEG can be considered the enteral feeding of choice for cancer patients with a reasonable survival expectation.

In our study, health and social care costs were estimated to be high both prior to surgery and at follow up, at about £7000 per annum including food or £5500 excluding food, with some £2500 per annum for hospital care, £350 per annum for physiotherapy and £172 per annum for general practice costs. There is no statistically significant difference in the estimates of costs at baseline or follow up, with the exception of a significant reduction in community care costs and general practice care for home visits. There are variations between children for all costs and the fairly high standard errors contribute to the non significance of the differences although these were not substantial. We would have liked a larger and longer study but were limited by time and resources. These studies are very difficult to carry out and this is one of the largest studies in this area. The number of children included was limited by taking only those for whom data at both baseline and follow up was available, but the standard errors were considerably reduced by basing the analysis on individual cost differences – each child being his/her own control.

At baseline the decision had already been made to place the gastrostomy. At follow up, use of services may be affected by the aftermath of the surgery. It is likely therefore that costs may be inflated at both points, and there may be some substitution of hospital for general practice care in the post surgery period. We should have preferred longer follow up, to when most children would have been less affected by the surgery aftermath, resource use would have settled more and would probably have been lower. The estimates reported here can only be considered as indicative, but clearly indicate that the outcome is cost neutral.

Conclusion

Prior to surgery two-thirds of the children had severe weight deficit for their age. It is now well established that appropriate use of gastrostomy, as in this study, results in significant catch up weight, other health gains and reduction in stress to families. The care demands for this group of severely disabled children are high

The study suggests that the outcome of gastrostomy placement is cost neutral, and as the associated clinical study confirmed positive health benefits, the indication is that the procedure for this group of children is cost effective.

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Conflict of interest None

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What is already known

- Neurologically impaired children commonly suffer malnutrition and growth deficiency
- The cost of their health care is high
- Gastrostomy placement results in significant catch-up weight, increase in mid-arm circumference and reduced drooling, vomiting, care demands and stress to carers

What this study adds

- Costs of hospital care including surgery, community and private health care and food are estimated before and after surgery
- No difference was found in mean overall costs; community costs were lower after surgery
- There is good indication that gastrostomy placement is cost neutral with positive benefits and is cost-effective

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