

Timing of gastrostomy insertion in children with a neurodisability: a cross-sectional study of early versus late intervention

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ABSTRACT

Objectives: The aim of the study was to assess whether gastrostomy placement before 18 months of age results in a greater increase in z-score for weight and to assess whether admission rates were reduced postgastrostomy in this age group.

Design: Retrospective cross-sectional study.

Setting: Single-centre secondary care District General Hospital.

Participants: All children with a neurodisability with a gastrostomy in situ in September 2011 were included. Those with primary neoplasia and undergoing chemo or radiotherapy or being palliated for an aggressive neurodegenerative disorder were excluded. Those with cystic fibrosis, primary congenital heart disease or Inflammatory bowel disease were also excluded. Forty-one children underwent final analysis. Twenty-four children underwent gastrostomy insertion less than 18 months and 17 children were older than 18 months.

Primary and secondary outcome measures:

Primary outcome was z-scores for weight immediately pregastrostomy and 12 months postgastrostomy. Secondary outcomes were hospital admission rates pregastrostomy and postgastrostomy. Values were compared for those with gastrostomy insertion less than or equal to 18 months against those older than 18 months at insertion.

Results: Z-score for weight increased significantly in both age groups. There was significantly increased mean difference in the z-score for weight of +1.33 pregastrostomy and postgastrostomy in the less than 18 months age group as compared with an increased mean difference in the z-score for weight of +0.45 in the older age group ($p=0.021$). There was no significant difference in the admission rates postgastrostomy insertion in either age group.

Conclusions: Gastrostomy insertion before 18 months of age results in greater z-score for weight gain in children with a neurodisability. This conclusion is limited by the lack of height and skin-fold thickness measurements. Further long-term matched control studies are required to determine the neurodevelopmental and clinical benefit of early gastrostomy placement in such children.

ARTICLE SUMMARY

Article focus

- Does gastrostomy placement before 18 months of age lead to greater final z-scores for weight than when placed after 18 months of age.
- Does gastrostomy placement before 18 months of age lead to reduced admission rates postgastrostomy than when placed after 18 months of age.

Key messages

- Gastrostomy insertion in children with a neurodisability results in a significant increase in z-score for weight in <18 and >18 months age groups.
- There is a greater increase in z-score for weight 12 months postgastrostomy for children less than 18 months.
- There is no difference in the admission rates pregastrostomy and postgastrostomy for children with gastrostomy insertion <18 or >18 months.

Strengths and limitations of this study

- The study is pragmatic and reflects the burden of neurodisability in a DGH hospital.
- The study is limited by a lack of height or skin fold thickness measurements.

INTRODUCTION

Children with complex developmental disabilities are known to have significant feeding difficulties and consequent problems with poor weight gain and nutrition.¹ This has been shown to adversely affect their health and societal participation.² Low weight has also been associated with increased mortality in this group of children.³ Feeding difficulties are common in this population due to a combination of poor oro-motor coordination, manual function and cognitive impairments and can result in significant nutritional deficits. Nutritional deprivation during sensitive periods of rapid neurodevelopment can lead to neurochemical changes within brain cells influencing cell function and structure. This

may result in long-lasting deficits in intelligence and school performance.⁴

Gastrostomy placement and feeding alleviates the need for oral feeding and significantly improves general health as measured partly by hospital admissions in this group of children.⁵⁻⁷ It is also well established that z-scores for weight increase postgastrostomy.⁵⁻⁸

These benefits have led to a gradual change in clinical practice as evidenced by the increase in prevalence of gastrostomy feeding over the last 20 years. Insertion rates have risen from 5% to 14% in this population.¹⁻⁹ The age of gastrostomy insertion in previous studies has ranged from 21 to 52 months with a growing trend towards gastrostomy placement at a younger age⁹ and parents would seem to support earlier gastrostomy placement.¹⁰ It was shown by Dahlseng *et al*⁹ that earlier gastrostomy placement leads to increased final z-scores; however, this study did not specify the timing of z-score for weight measurement postgastrostomy nor the difference in z-score pre-gastrostomy and postgastrostomy. The timing of gastrostomy placement remains unclear.

Although early gastrostomy placement may be beneficial, the benefits need to be balanced with the risks such as postoperative complications or infection. Complication rates can vary from 11.2% to 20% in this population.⁸⁻¹¹ Westbrom *et al*¹² also reported a ninefold increased risk of death in children with cerebral palsy (CP) who are gastrostomy fed.

Despite the difficulties of balancing risk versus benefit for gastrostomy insertion in the light of current knowledge, it remains necessary to facilitate the decision-making process of when to insert gastrostomies in children with a neurodisability.

We therefore seek to ascertain whether all children with complex needs should have gastrostomy placement at an earlier age. We conducted a study in a population reflecting the typical District General Hospital clinician's distribution of developmental disability. We assessed whether gastrostomy insertion before 18 months of age resulted in a greater difference in z-score for weight postgastrostomy than insertion after 18 months of age. We also examined whether general health was improved to a greater extent in the younger age group using admission rates as a surrogate health measure.

METHOD

This was a retrospective cross-sectional study with data obtained from case-notes. We identified all children in South Northamptonshire who had a gastrostomy in situ in September 2011. Weight values were read 1 month pre-gastrostomy and 12 months postgastrostomy from growth charts or from documentation in notes. Timing of gastrostomy and weight values were taken at corrected for gestation age in all preterm children. Demographic data and admissions data were obtained from case-notes and local databases. Weight data on children was obtained from school and case-note growth charts

retrospectively. Those with Cystic Fibrosis, primary congenital heart disease or Inflammatory Bowel Disease or a primary neoplasia and undergoing chemotherapy or radiotherapy or being palliated for an aggressive neurodegenerative disorder were excluded. Diagnostic criteria were based on International Classification of Diseases-10 coding.

The group was divided into those with gastrostomy insertion before 18 months and those with gastrostomy insertion after 18 months. These groups were chosen to reflect the observed distribution of age at gastrostomy insertion. Weight was converted to z-scores using the Coles LMS method¹³ with standard LMS data obtained from Centre for Disease Control growth chart data.¹⁴ The difference in z-score pre and postgastrostomy was then calculated for each patient and compared between groups.

Statistical analysis

Demographics were analysed using Fishers exact test and χ^2 analysis. Admission numbers, pre-gastrostomy and postgastrostomy z-score and z-score difference were compared using an independent samples t test. Data were entered and analysed using SPSSV.20.

RESULTS

Fifty-three children were identified. Seven children were excluded. There were insufficient data to analyse in a further five children. Of these five children three had gastrostomies inserted out of area without transfer of growth data and in two children growth data was missing from available notes.

Forty-one children were included in the final analysis with 24 children less than or equal to 18 months and 17 older than 18 months at gastrostomy insertion. Twenty children were female, 21 were male. Median (IQR) age at gastrostomy insertion in the younger group was 11.5 (6-13) months and in the older group was 68 (38-82) months.

There was a significant difference ($p=0.008$) in the rates of CP diagnosis between age groups. The most common primary reason for gastrostomy insertion was 'feeding difficulties' in both groups (table 1).

There was no significant difference in the number of admissions pre-gastrostomy and postgastrostomy overall ($p=0.384$) or within the younger group ($p=0.133$) or older group ($p=0.241$; table 2).

For the groups combined the mean z-score pre-gastrostomy was -2.94 (SD 1.76; 95% CI -2.8 to -1.5). Mean z-score for weight postgastrostomy was -1.87 (SD 1.31; 95% CI -1.66 to -0.65). Using a paired sample t test the increase in mean z-score for weight postgastrostomy was significant ($p<0.0001$). The increase in mean z-score for weight postgastrostomy was significant in the <18 month age group ($p<0.001$) as well as the >18 month age group ($p=0.033$; table 3). A plot of difference in z-score for weight against age at gastrostomy

Table 1 Demographics of groups

	Group 1 (≤ 18 months) n (%)	Group 2 (≥ 18 months) n (%)	p Value
Gender			
Male	13 (54.2)	8 (47)	0.609
Female	11 (45.8)	9 (53)	0.609
Reason for gastrostomy			
Poor Feeding	17 (71)	14 (82)	0.096
Prevent aspiration	1 (4)	1 (6)	0.628
Reflux	3 (12.5)	1 (6)	0.271
Poor weight gain	3 (12.5)	1 (6)	0.271
Primary Diagnosis			
Cerebral Palsy	1 (4.2)	7 (41.2)	0.008
Global impairment—unknown cause	1 (4.2)	1 (5.9)	0.628
Expremature 25–28 weeks gestation	3 (12.5)	0 (0)	0.065
Expremature 23–25 weeks gestation	3 (12.5)	0 (0)	0.065
Feeding difficulties—unknown cause	2 (8.3)	0 (0)	0.514
Chromosomal abnormality	6 (25.0)	2 (11.7)	0.450
Neuro—Metabolic	2 (8.3)	3 (17.6)	0.354
Congenital brain malformation	2 (8.3)	0 (0)	0.514
Other	4 (16.6)	3 (17.6)	0.792

insertion for the combined group revealed clustering of values at less than 18 months and greater than 48 months (figure 1).

The mean z-score for weight pregastrostomy in the <18 month group was -2.78 and in the >18 month group it was -1.17 . The mean z-score postgastrostomy in the <18 month group was -1.45 and in the >18 month group it was -0.72 . The z-score for weight pregastrostomy was significantly lower in the younger age group ($p=0.014$); however, there was no significant difference in z-score between the groups postgastrostomy ($p=0.178$). The mean difference in the z-score pregastrostomy and postgastrostomy was significantly greater in the younger age group than in the older group ($p=0.021$; table 3 and figure 2).

Eleven children had a decrease in z-score postgastrostomy. These children had a significantly higher baseline z-score pregastrostomy ($p=0.011$) but there were no other differences in admission rates or primary diagnosis. Seven children were long-term nasogastric (NG) fed immediately before gastrostomy insertion. These were all in the younger group. These children did not have a significantly increased pregastrostomy z-scores for weight compared with those children that were not NG fed ($p=0.54$).

DISCUSSION

Our study has shown that gastrostomy insertion under 18 months of age results in significantly greater difference in mean z-score for weight pregastrostomy and postgastrostomy as compared with placement over 18 months of age. However, the increase in z-score for weight postgastrostomy remains significant for both the early and late groups. This complements previous studies^{5–7 9} where a significant increase in z-score for weight postgastrostomy for the sample as a whole had been found. The improved difference in z-score at a younger age may be explained by the baseline z-score in the younger age group being significantly lower than the older age group and therefore a source of selection bias for early gastrostomy insertion. The z-score was also seen to decrease in a significant minority of children postgastrostomy; however, these children had higher baseline z-scores and the primary reason for gastrostomy insertion was not weight gain but poor feeding or risk of aspiration.

In our sample there was no significant difference in the hospital admission rates pregastrostomy and postgastrostomy in the early group ($p=0.133$) or the late group ($p=0.241$). This would suggest no clear clinical benefit

Table 2 Analysis of admissions

	Group 1 (≤ 18 months)	95% CI lower bound to upper bound	Group 2 (≥ 18 months)	95% CI lower bound to upper bound
Number of admissions pregastrostomy mean (SD)	6.00 (5.91)	3.71 to 8.37	2.12 (2.45)	1.18 to 3.35
Number of admissions postgastrostomy mean (SD)	4.38 (1.92)	2.92 to 6.01	2.94 (3.82)	1.41 to 4.76
p Value	0.133	N/A	0.241	N/A

Table 3 Analysis of z-score

	Group 1 (≤ 18 months)	95% CI lower bound to upper bound	Group 2 (≥ 18 months)	95% CI lower bound to upper bound	p Value
z-Score pregastrostomy mean (SD)	-2.78 (2.23)	-3.72 to -1.97	-1.17 (1.56)	-1.95 to -0.47	0.014
z-Score postgastrostomy mean (SD)	-1.45 (1.92)	-2.21 to -0.71	-0.72 (-1.24)	-1.37 to -0.18	0.178
p Value	<0.001	N/A	0.033	N/A	N/A
z-Score difference mean (SD)	+1.33 (1.51)	0.75-1.91	+0.45 (0.79)	0.09-0.82	0.021

to early versus late gastrostomy insertion although hospital admission rates are a crude surrogate measure of general health and should only form part of a more complete assessment.⁵ Specific complications or adverse effects of the gastrostomy itself were not addressed.

Our study is limited by the low numbers and with the data being collected retrospectively. It is also limited by the self-constrained time-limits on data collection to 12 months postgastrostomy. The population is more heterogeneous than previous studies; however, this does reflect the typical burden of neurodisability in a District General Hospital. The nutritional requirements and therefore the growth of preterm children or children with a neurometabolic disorder may differ from term children with CP. This would result in varying growth potential and thereby varying response to gastrostomy insertion.

There is a selection bias in the older age group towards children with CP but this reflects the timing of diagnosis. Although not statistically significant there are

an increased number of preterm children in the younger age group. A study on growth in the EPICure cohort showed that preterm children born of average weight were lighter than expected at term but showed catch-up by 0.5 SD at 30 months corrected age.¹⁵ This may be the cause of the increase in z-score difference observed in the early group although the EPICure study does not comment on the use of gastrostomy insertion in this population.

Z-score is an incomplete measure of nutritional status as skin-fold thickness, height and head circumference are also important parameters that have not been examined. There were too few height data points to analyse in this group of patients due to the short timeline post-gastrostomy examined. Without height measurements we cannot comment on obesity or nutritional status in this population.

Children with a neurodisability are not excluded from the secular trend of increasing childhood obesity.¹⁶



Figure 1 Box and whisker plot of z-score difference and age group.

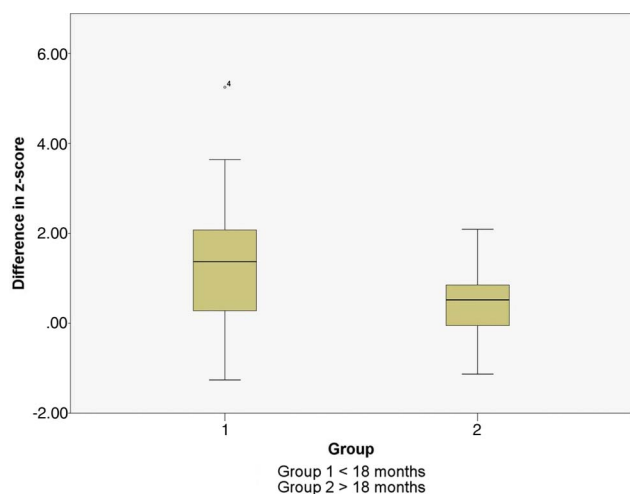


Figure 2 Scatter plot of age at gastrostomy and z-score difference.

If gastrostomy placement before 18 months resulted in an increased weight velocity leading to obesity, this may have a negative impact on carer's ability to cope. Recent literature suggests that the increased weight gain from gastrostomy feeding tends to be from both fat and protein accumulation and does not result in higher fat index proportions alone.^{17 18} The results of our study also suggest that gastrostomy placement has resulted in better nutritional status in an underweight population as opposed to an underweight population becoming overweight. However, these results must be interpreted with caution due to the lack of height or skin-fold thickness measurements in this study.

Over the last two decades increasing numbers of children have undergone gastrostomy placement and derived greater benefit in quality of life and ease of administration of nutrition and medicines.^{1-5 10} Many parents report that they wish the intervention had taken place earlier and certainly the reduced time taken for feeds and the increased ease of administering multiple medications results in a positive impact on family life.¹⁹ Significant neurodevelopmental progress accompanies improved nutritional status in children with CP.¹¹ It has also been postulated that earlier timing of nutritional supplementation intervention can result in a greater neurodevelopmental benefit.²⁰ It is therefore assumed that if early gastrostomy feeding results in improved nutrition, this in turn results in improved neurodevelopmental outcome. This remains an assumption that warrants further investigation.

Long-term match controlled studies lasting over a decade or longer will be necessary to determine, if present, the extent of any potential neurodevelopmental and clinical benefit for this group of children. However, this study reveals significant differences in weight gain between early versus late gastrostomy insertion. This conclusion is limited by the lack of other anthropometric measurements in this study but it is clear that further

work needs to be done to clarify the advantages of early gastrostomy placement.

CONCLUSION

Gastrostomy insertion before 18 month of age results in greater increase in z-score for weight in children with a neurodisability although clinical and neurodevelopmental benefit remains uncertain. With increasing numbers of children undergoing gastrostomy insertion and now surviving beyond childhood into adulthood, the question arises as to whether optimum long-term benefit could be achieved by gastrostomy placement before 18 months of age within this patient group.

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Contributors AW conceived the original idea of the paper. RS designed the study and collected the data. RS and WZ completed the statistical analysis of the data. RS completed the first draft of the manuscript. All three authors participated in redrafts and approval of the final manuscript.

Competing interests None.

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