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Parent-Reported Effects of Gastrostomy Tube Placement

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Abstract

Background: For children with major feeding problems and their parents, meals may be unpleasant. We aimed to evaluate how insertion of a gastrostomy tube influenced parent-child communication and satisfaction during meals, as well as duration of meals, oral intake, vomiting, and growth. **Materials and Methods:** Children admitted for a gastrostomy tube placement were included. Age, sex, diagnosis, and preoperative nasogastric tube were registered. Weight, height, oral feeding, duration of meals, and vomiting were assessed preoperatively and 6 and 18 months postoperatively. We used a numeric rating scale to assess parent-reported parental stress, child satisfaction, parent satisfaction, and parent-child communication during meals at all 3 time points. **Results:** Fifty-eight children were included: 33 boys and 25 girls. Median age was 1.7 years (range, 0.5–14.7 years). Thirty-nine were neurologically impaired, and 44 had a nasogastric tube for a median of 7.5 months (range, 0.5–28 months) preoperatively. Child satisfaction ($P = .001$), parent satisfaction ($P = .006$), and parent-child communication ($P = .026$) during meals were significantly improved 18 months after receiving a gastrostomy tube. Vomiting was reduced in 42%, oral intake increased in 49%, and weight-for-height percentile increased in 55% of the children. **Conclusions:** In children with major feeding problems, a gastrostomy tube improved parent-child communication and satisfaction during meals. Furthermore, oral intake was increased, and vomiting was reduced. Growth improved in around half of the children. (*Nutr Clin Pract.* XXXX;xx:xx-xx)

Keywords

gastrostomy; children; meals; growth; feeding and eating disorders of childhood; enteral nutrition

Feeding is an important arena for interaction between parents and children. Meals are usually enjoyable events, but for children with major feeding problems, meals can be far from pleasant. Not only the child's inability to eat, but also the parents' reaction to the feeding situation may interfere with the child's health and thriving. Parents report that meals may be stressful and that problems with feeding their child lead to extreme focus on nutrition intake and frustration in both children and parents.¹⁻⁴ When long-term tube feeding is necessary, a gastrostomy tube is generally preferred to a nasogastric tube because the nasogastric tube is easily displaced, uncomfortable, and more noticeable than a gastrostomy tube.⁵⁻⁷

Weight increase after gastrostomy placement is well documented,⁸⁻¹² but whether the gastrostomy tube has a positive effect on well-being is debatable.¹³⁻¹⁵ Therefore, we wanted to examine how parents considered the gastrostomy tube influenced parent-child communication, satisfaction, and stress during meals. Furthermore, we report changes in meal duration, oral intake, vomiting episodes, and growth in children with feeding problems who underwent gastrostomy tube placement for long-term tube feeding.

Materials and Methods

Participants

Eighty-seven children with major feeding problems referred to a tertiary hospital for gastrostomy tube placement between

January 2003 and December 2005 were all eligible for the study. Children with parents who did not speak Norwegian, children receiving a gastrostomy tube in the newborn period, and those undergoing other procedures concomitantly were not included. The newborn period was defined as the first 4 weeks of life or until 44 gestational weeks. Fifty-eight children and their parents met the inclusion criteria and agreed to participate in the study. Two families refused to participate. The study population is presented in Figure 1.

Methods

Parents were interviewed and answered questionnaires 0–3 days before the gastrostomy tube was inserted (T0) and then at

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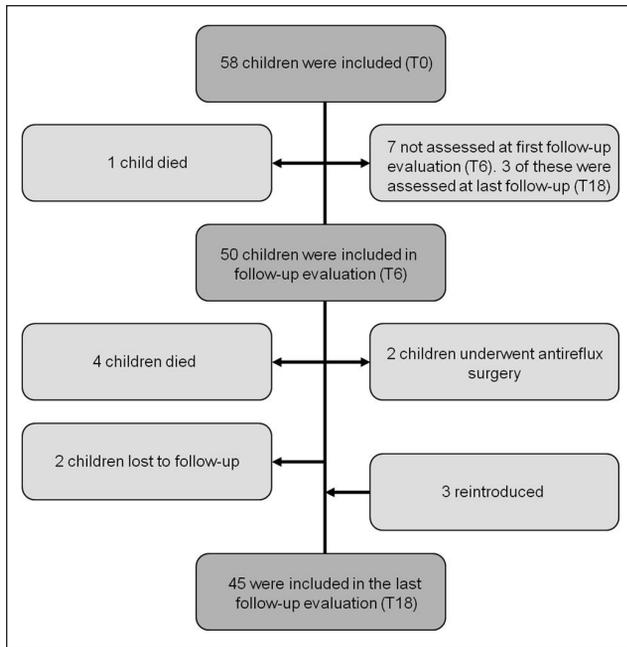


Figure 1. Children included in the study at the different time points.

6 (T6) and 18 months (T18) postoperatively. The first 2 (T0 and T6) assessments took place at the hospital and were partly a semi-structured interview and partly a self-report questionnaire. The last assessment (T18) was performed by telephone, and the self-report questionnaire was mailed and returned in a prestamped envelop. All children had routine follow-up at the local hospitals.

Most of the children in this study had neurological impairment and were too young to respond to questionnaires. Thus, the questionnaires were answered by 1 parent, and the same parent answered at all 3 assessments. We wanted to register both medical and nutrition variables, as well as well-being during meals. Since no validated and suitable questionnaire covers all these aspects, we designed a self-report questionnaire. The questionnaire was tested in a pilot study, and some of the questions were adjusted for clarification.

Child Data

Age, sex, and diagnosis of the children were registered. Weight and height were registered at all 3 time points. At T0 and T6, weight and height were measured at the hospital, whereas at T18, weight and height were recorded at the local hospital or healthcare service. Unfortunately, weight and height were registered in only 53, 43, and 30 children at T0, T6, and T18, respectively. We used the Norwegian normative sample for weight-for-height and height-for-age, and the ≤ 2.5 th percentile was considered low weight/height.¹⁶ At admission for gastrostomy placement, the parents reported the main indications for placement of a gastrostomy tube and whether the child had a

nasogastric tube. Before (T0) and after (T6 and T18) receiving a gastrostomy tube, the parents also reported the following data: quantification of how much the child ate orally and how much was given through the tube, main nutrition route (only tube fed, mostly tube fed [$>50\%$ of total intake], mostly oral [$>50\%$ of total intake], only oral), meal duration, and presence of vomiting. Change in the amount of oral intake was reported as unchanged, decreased, or increased. Meal duration was defined as the mean time in minutes used per meal as reported by parents. Vomiting was reported as daily, weekly, monthly, or never. Change in the frequency of vomiting was reported as unchanged, reduced, or increased. The parents also reported whether they had received nutrition advice from a dietitian.

Parents' Experiences During Meals

The parents were asked in the questionnaire to rate parental stress, child and parent satisfaction, and parent-child communication during meals on a numeric rating scale from 1–10, where 1 indicated the lowest level of stress, the highest child and parent satisfaction, and the best parent-child communication (Figure 2). Parental stress was defined as a feeling of stress and discomfort. Parent satisfaction was defined as the parents' well-being and happiness. Child satisfaction was defined as the parents' impression of the child's well-being and happiness. Parent-child communication was defined as experienced verbal and nonverbal interaction between parents and children.

Statistical Analysis

Not all parents answered all questions at all 3 time points, resulting in missing data. Percentages are presented for the number answering and not for the whole study population. Unless otherwise stated, the numbers are given as mean and standard deviation (SD). For comparison of groups with or without a preoperative nasogastric tube, as well as neurologically impaired and neurologically normal children, we used independent sample *t* test and Pearson's χ^2 as appropriate. We used linear mixed models with a random intercept term to analyze continuous variables over time. Linear mixed models is an extension of regression analysis to model repeated measurements. The method assumes that missing data are missing at random and may be more resilient than other methods when the response rate is low. For comparison of repeated dichotomous data, we used the McNemar test and compared T0 with T6 and T18, respectively. *P* values $< .05$ were considered statistically significant. Analyses were performed using PASW version 18 (SPSS, Inc, an IBM Company, Chicago, IL).

Ethics

The study was approved by the Regional Ethics Committee for Medical Research. Parents of children referred to the hospital for a gastrostomy tube placement were contacted

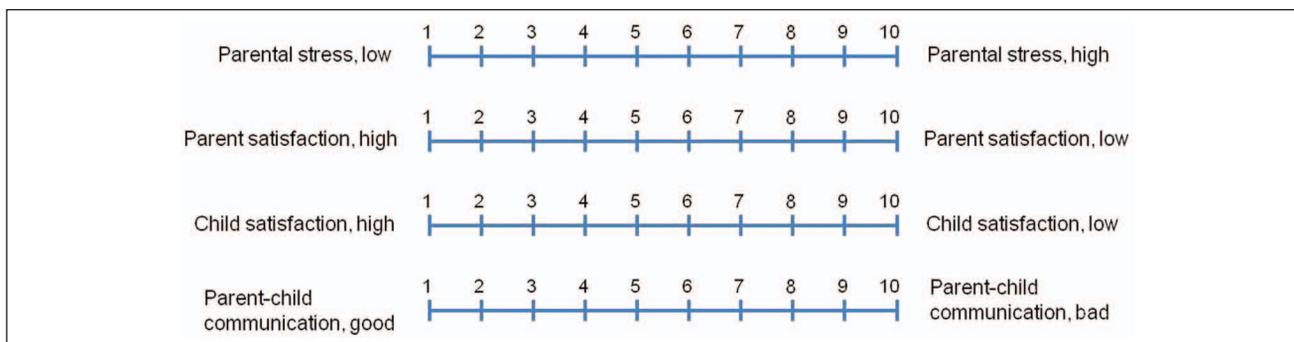


Figure 2. The scales used to rate the parents’ experiences during meals both before and after the placement of a gastrostomy tube in the child.

Table 1. Main Indications for Gastrostomy Tube Feeding in 47 Children With Major Feeding Problems as Reported by Their Parents.

Indication	No. (%)
Swallowing and/or oral motor difficulties	26 (55)
Inadequate weight gain	22 (47)
Vomiting	19 (40)
Food refusal	18 (38)
Time-consuming meals	13 (28)
Other ^a	4 (9)

Each patient could have more than one indication.

^aOther indications for gastrostomy included long-term tube feeding, discomfort with the nasogastric tube, and easier administration of medication.

and invited to participate in the study when the child was admitted to the hospital. Consent was obtained after giving oral and written information.

Results

Child Data

The study population included 33 (57%) boys and 25 (43%) girls. Median age was 1.7 years (range, 0.5–14.7 years). Thirty-nine (67%) were neurologically impaired, 10 (17%) had congenital heart disease, and 9 (16%) had other diagnoses, including respiratory and gastrointestinal diseases. Parents reported that 26 (45%) of the children had swallowing and/or oral-motor difficulties. Preoperatively, 44 (76%) had used a nasogastric tube for a median of 7.5 months (range, 0.5–28 months).

Main indications for insertion of a gastrostomy tube, as reported by the parents, are listed in Table 1. Swallowing and/or oral-motor difficulties and inadequate weight gain were most frequently reported. It was more common for parents of children with a preoperative nasogastric tube to report vomiting and time-consuming meals as indications for a gastrostomy than for parents of children without a preoperative nasogastric tube ($P = .002$ and $P = .023$, respectively).

Twenty-one of 50 (42%) at T6 and 23 of 45 (51%) at T18 reported that they had received nutrition advice from a dietitian. Nine reported that they received nutrition advice from a dietitian at both T6 and T18.

The percentage of children with height-for-age ≤ 2.5 th percentile did not change after gastrostomy tube placement, being 29 of 53 (55%) before and 17 of 30 (57%) 18 months after gastrostomy tube placement. There was no difference between neurologically impaired and neurologically normal children.

Weight-for-height percentile was ≤ 2.5 in 19 of 53 (36%) children before receiving a gastrostomy tube, and there was no difference between children with and without a preoperative nasogastric tube (Table 2). Sixteen of 30 children (53%) had increased their weight-for-height percentile 18 months after gastrostomy tube placement. Among 13 children with inadequate weight as the main indication for gastrostomy and with weight registered, 9 (70%) had increased their weight-for-height at T18. Preoperatively, low weight-for-height was more common in neurologically impaired than in neurologically normal children ($P = .023$). At T18, there was no difference between these groups.

Eighteen months after gastrostomy tube placement, 6 of 30 (20%) children had a weight-for-height ≥ 97.5 th percentile (Table 2). Of the 6 children who were obese at T18, 3 had been in contact with a dietitian at either T6 or T18 and 2 throughout the study period.

Preoperatively, the duration of meals was the same in children with and without a nasogastric tube ($P = .285$). The parents did not report that the child spent less time on meals after placement of the gastrostomy tube ($P = .174$) (Table 3).

Preoperatively, tube feeding was the main nutrition route in 33 of 58 (57%) children. Postoperatively, the gastrostomy tube was the main nutrition route in 33 of 50 (66%) at T6 and in 27 of 45 (60%) at T18 (Table 3). Although the gastrostomy tube was the main nutrition route for the majority of children, parents reported that oral intake had increased in 17 (34%) children after 6 months and in 22 (49%) after 18 months (Table 3). Reduced oral intake after receiving a gastrostomy tube was not reported in any child. There were no differences between

Table 2. Weight-for-Height Percentiles in Children With Major Feeding Problems Before (T0) and 6 (T6) and 18 (T18) Months After Gastrostomy Placement.

Weight-for-Height	T0 (n = 53), No. (%)	T6 (n = 43), No. (%)	T18 (n = 30), No. (%)
≤2.5th percentile	19 (36)	12 (28)	7 (23) ^a
10th, 25th, and 50th percentiles	24 (45)	26 (60)	15 (50)
75th and 90th percentiles	9 (17)	3 (7)	2 (7)
≥97.5th percentile	1 (2)	2 (5)	6 (20)

^a $P = .18$, McNemar test comparing T0 with T18.

Table 3. Duration of Meals, Main Nutrition Route, Oral Intake, and Vomiting in Children With Major Feeding Problems Before (T0) and 6 (T6) and 18 (T18) Months After Gastrostomy Tube Placement, as Reported by Parents.

Variables	T0 (n = 58)	T6 (n = 50)	T18 (n = 45)	P Value
Meal duration, min, median (range)	60 (3–180)	40 (10–240)	35 (5–180)	.174 ^a
Mainly tube fed, No. (%)	33 (57)	33 (66)	27 (60)	1.0 ^b
Increased oral intake, No. (%)		17 (34)	22 (49)	
Reduced vomiting, No. (%)		20 (40)	19 (42)	

^aLinear mixed models.

^bMcNemar test comparing T0 and T18.

Table 4. Well-Being During Meals Before (T0) and 6 (T6) and 18 (T18) Months After Gastrostomy Tube Placement in Children With Major Feeding Problems, as Reported by Parents.

Meal Factors	T0 (n = 44)	T6 (n = 42)	T18 (n = 39)	P Value ^a
Parental stress	5.10 (2.55)	4.28 (2.66)	3.77 (2.71)	.015 ^b
Parent satisfaction	5.40 (2.55)	4.35 (2.50)	3.50 (2.35)	<.001 ^c
Child satisfaction	4.97 (2.40)	3.98 (2.51)	2.81 (2.04)	<.001 ^c
Communication	4.57 (2.50)	3.78 (2.59)	2.57 (2.06)	.001 ^b

Scores from 1 to 10, with 1 representing “best score.” Values are presented as mean (SD).

^aLinear mixed models.

^bDifferences significant between T0 and T18.

^cDifferences significant between T0 and T18, and T6 and T18.

children with and without a preoperative nasogastric tube with respect to increased oral intake after gastrostomy tube placement ($P = .384$ and $P = .924$ at T6 and T18, respectively).

Before gastrostomy tube insertion, parents reported daily vomiting in 18 of 58 (31%) children. All 18 children had a nasogastric tube. Eighteen months (T18) after the gastrostomy tube placement, 9 of 45 (20%) children reported daily vomiting ($P = .55$). However, the frequency of vomiting was reduced in 20 of 50 (40%) children at T6 and in 19 of 45 (42%) at T18 (Table 3). Importantly, none reported increased frequency of vomiting. Two children underwent antireflux surgery between 6 and 18 months after gastrostomy tube placement and were then excluded. Both had neurological impairment, and the frequency of vomiting was unchanged 6 months after the gastrostomy placement.

Parent-Reported Experiences of Meals

The parents reported reduced stress, increased satisfaction for both child and parents, and improved parent-child communication during meals (Table 4).

Discussion

Parents of children with major feeding problems reported increased satisfaction and better parent-child communication during meals after insertion of a gastrostomy tube in the child. Since interaction between parents and children during meals is important for the child's growth and development, it is important that meals are as pleasant as possible for children with feeding problems. Our results confirm other reports showing

increased caregiver satisfaction during meals after insertion of a gastrostomy tube.^{4,17} The gastrostomy tube makes administration of nutrients, fluids, and medications easier and may reduce parents' concern about the nutrition status of the child.^{14,18}

Preoperatively, parents of children with and without a nasogastric tube reported similar results of satisfaction and parent-child communication during meals. This important finding suggests that tube feeding by a nasogastric tube does not improve satisfaction in the same way as gastrostomy tube feeding does. This is in accordance with Heine et al,¹⁹ who reported reduced family and child distress during feeding after gastrostomy tube insertion and that parents were happier with the gastrostomy tube than with the nasogastric tube. However, despite several reports of positive effects of a gastrostomy tube placement as compared with feeding by a nasogastric tube, many mothers struggle to accept that the child needs a gastrostomy, and for these reluctant mothers, information about other parents reporting satisfaction with the gastrostomy tube is important.

Twenty-eight percent of parents reported time-consuming meals as one of the main indications for giving the child a gastrostomy tube. Previous studies have reported that gastrostomy feeding reduces the time spent on meals in children with feeding problems.^{11,14,20} In the present study, there was a clear trend toward reduced length of meals, although this did not reach statistical significance, probably because of the small study population and a wide range in meal duration. Furthermore, a high number of the children were already being fed through a nasogastric tube before receiving a gastrostomy tube. Last, the questionnaires did not differentiate between time spent on oral and tube feeding.

Oral intake was increased in half of the children and was not reduced in any child. This is in accordance with previous reports.¹⁸ Improved satisfaction during meals, removal of the nasogastric tube, and improvement in the child's physical and psychological well-being may all contribute to increased oral intake. Several studies have claimed that a nasogastric tube can promote food refusal and other feeding difficulties.^{5,21} Therefore, removal of a nasogastric tube can stimulate increased oral intake.

How gastrostomy tube placement affects gastroesophageal reflux symptoms is much debated.²²⁻²⁴ Preoperatively, 31% of the children were reported to have daily vomiting. Although the actual percentage of children who were reported to have daily vomiting was not reduced, parents reported that 40% of the children vomited less after receiving the gastrostomy. We do not know why vomiting was reduced after receiving the gastrostomy tube, but all children with daily vomiting preoperatively had a nasogastric tube, and one might speculate that a nasogastric tube may worsen vomiting problems, as reported by others.^{7,25} However, we do not know if these children also had daily vomiting before receiving a nasogastric tube or if these problems started when the nasogastric tube was placed.

As many as 19 of 53 children were underweight (weight-for-height ≤ 2.5 th percentile) before the gastrostomy tube

placement. This reflects that inadequate weight gain was reported to be one of the main indications for a gastrostomy tube. We had expected better growth after gastrostomy tube placement since many previous studies have reported significant weight gain after gastrostomy placement.⁸⁻¹² There may be several reasons for the lack of growth seen in our study. The child's underlying disease, gastroesophageal reflux, or recurrent infections may contribute to poor growth. Furthermore, 67% of the children in our study were neurologically impaired. We compared the children's growth with standards for normally developed children. For children with neurological impairment, it has been hypothesized that neurological and endocrine factors contribute to suboptimal growth, and therefore it is not ideal to compare these children with normative samples from healthy children.^{26,27} Only a minority of the children had been followed by a dietitian through the whole study period, and this may also contribute to poorer growth.

Weight continued to change throughout the study period, and it seems important to monitor and evaluate growth, even several months after a gastrostomy tube placement. Interestingly, we found that 20% of the children were obese 18 months after the gastrostomy placement. Obesity is particularly detrimental for children with motor difficulties, and previous studies have highlighted the potential risk of overfeeding children via a gastrostomy tube.^{8,28}

In this study, we asked the parents to rate their own satisfaction, the child's satisfaction, parent-child communication, and parental stress during meals on a scale from 1 to 10, using a self-constructed questionnaire. Most other studies that have evaluated the effects of gastrostomy tube feeding on meals have used qualitative methods such as interviews.^{13,14,17} Interaction between child and parent during meals is important for the child's development. Although the child's verbal and nonverbal communicative expressions change during development in the first years of life, the parent's experience of the quality of the parent-child communication is not supposed to be influenced by this development. Thus, the significant improvement in parent-child communication reported by the parents throughout the 18-month study period may well be a consequence of the gastrostomy tube placement and not just attributed to the child's increasing age. Ideally, we could have used more advanced observational assessments such as the Parent-Child Early Relational Assessment, which is a standardized and validated method assessing parent-child interaction, or other assessment scales, and we could have asked the parents to register irritability, crying, smiling, and similar behavior during meals to add more information on the child's well-being.²⁹⁻³¹ However, these assessment tools are labor intensive and difficult to implement in a clinical setting.

In the present study, we found that gastrostomy tube feeding improved parent and child satisfaction and parent-child communication during meals. This should be taken into account when giving information to parents and prioritizing patients for gastrostomy insertion. The information we have gathered from the parents suggests that the time

with a nasogastric tube should be kept as short as possible, as recommended by the European Society for Clinical Nutrition and Metabolism (ESPEN).⁷ Many of the children with severe feeding problems in the present study were not followed by a dietitian. We recommend that children should be offered a multidisciplinary follow-up, including a dietitian, after a gastrostomy tube placement.

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