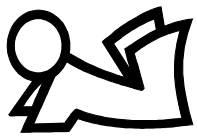
ROYAL CHILDREN'S HOSPITAL

HOME ENTERAL NUTRITION REPORT

DEVELOPMENT OF VICTORIAN PAEDIATRIC DISEASE-SPECIFIC GUIDELINES



Home Enteral Nutrition Working Party

Royal Children's Hospital, Melbourne

MAY 2000

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GLOSSARY OF TERMS

HEN	Home Enteral Nutrition
RCH	Royal Children's Hospital
CF	Cystic fibrosis
CP	Cerebral palsy
AuSPEN	Australian Society for Parenteral and Enteral Nutrition
FEV1	Forced expiratory volume - 1 second
GOR	Gastro-oesophageal reflux
HAZ	Height-for-age Z score
PEG	Percutaneous Endoscopic Gastrostomy
PEM	Protein-energy malnutrition
QOL	Quality of life
WAZ	Weight-for-age Z score

EXECUTIVE SUMMARY

In August 1997, The Honourable Robert Knowles, former Minister for Health, launched a funding initiative for Home Enteral Nutrition (HEN). This initiative by the Victorian Government has provided the support necessary for the Royal Children's Hospital, Melbourne, to develop a HEN Service based on the best practice guidelines set out by the Australian Society for Parenteral and Enteral Nutrition (AuSPEN). Although the benefits of a HEN Service were widely accepted there was a need for critical evaluation of health and quality-of-life outcomes, cost-effectiveness of HEN therapy and best practice guidelines. This report summarises the findings of a collaborative research project at the Royal Children's Hospital.

Based on a retrospective review performed in 1997, the Royal Children's Hospital is responsible for the management of about 50% of all Victorian patients (adults and children) receiving HEN. Several groups of children with chronic illness are at particular risk of malnutrition and often require nutritional support or rehabilitation. These include children with chronic malabsorption, neurological impairment or cystic fibrosis. The present report summarises the findings of several retrospective and prospective studies in tube-fed children. These studies formed the basis for the development of disease-specific best practice guidelines in children with cystic fibrosis and cerebral palsy.

Cerebral palsy

Retrospective study. Medical records of all patients with cerebral palsy (CP) who had undergone gastrostomy placement between 1990 and 1997 were reviewed. Of 69 patients, 44 (64%) had a percutaneous endoscopic gastrostomy (PEG), and in 25 (36%) the tube was placed surgically. The mean age at gastrostomy placement was 5.8 years. About half of the patients had a period of nasogastric tube feeding prior to gastrostomy placement. Weight gain was observed in all patients after gastrostomy placement (mean weight gain 5.0 kg ± 3.3 in the first

12 months after the procedure). Thirty percent of patients required fundoplication for treatment of GOR disease or pulmonary aspiration.

Most of the patients achieved their estimated nutritional requirements (mean energy provided 89 ± 16% of estimated energy requirements). About 2/3 of patients received concentrated feeds of 1 kcal/mL (420 kJ/100 mL). Twenty-three (30%) patients required more concentrated feeds. Most patients (67%) tolerated bolus feeds administered by gravity feeding set. Sixteen percent of patients required continuous pump infusion in order to avoid vomiting after feeds.

Nineteen (28%) of the patients died within the study period. There was no procedure-related mortality associated with gastrostomy placement. The high mortality reflects the severity of the underlying disease. No deaths were directly attributed to the gastrostomy tube. Respiratory complications were assumed as the cause of death in 5 of 19 patients, one of whom had undergone fundoplication.

Prospective study. From November 1998 to February 2000, 25 patients with CP underwent gastrostomy placement. The mean age at gastrostomy was 6.8 years (SD ± 5.75; range 0.7 to 22). Twenty-one (84%) received a percutaneous endoscopic gastrostomy, and 4 (16%) a surgical gastrostomy. The surgical technique was chosen in 3 patients because of severe GOR which required fundoplication, and in one patient were PEG could not be safely achieved.

Of 16 patients undergoing oesophageal 24-hour pH monitoring, 5 (31%) had evidence of increased GOR. In 20 patients endoscopic biopsies were taken at the time of endoscopic gastrostomy placement. Of these, 14 (70%) had evidence of oesophagitis. Nuclear medicine gastric emptying studies were performed preoperatively in 16 patients, and 25% of these had evidence of delayed gastric emptying.

All patients were markedly malnourished at the time of PEG placement (mean Z score for weight-for-age –2.36 ± 1.52). There was significant weight gain within 3-6 months of gastrostomy placement (Z score –1.79 ± 1.80); p = 0.03.

Conclusion: Gastrostomy placement was well tolerated in malnourished patients with CP. There was no procedure-related mortality. The nutritional status improved significantly within 6 months of gastrostomy placement. Patients should be carefully assessed for the presence of GOR disease. A surgical antireflux procedure was required in about 30% of patients with severe GOR disease and/or recurrent pulmonary aspiration. The prospective study is ongoing.

Cystic fibrosis

Retrospective study. Gastrostomy placement has become common practice in children and adolescents with cystic fibrosis (CF) requiring nutritional rehabilitation. There is still controversy about the optimal timing of the gastrostomy and long-term clinical outcomes. All CF patients undergoing gastrostomy between 1990 and 1998 were reviewed. Clinical information was collected from medical records. Serial measurements of weight (weight-for-age z scores; WAZ) and FEV1 (% predicted) were taken in the 2 years before and the 2 years after gastrostomy, and mean values (±SD) for each year were compared by *t*-test.

Thirty-six patients underwent gastrostomy (mean age 11.6; SD 4.82, range 3.1 - 20.2 yrs; 21 M, 15 F). In 31 patients gastrostomies were placed endoscopically (PEG); 5 underwent surgical gastrostomy and fundoplication because of GOR and suspected aspiration.

Eleven patients (8 female, 3 male) died within 2 years post gastrostomy. There was a significant decrease in mean WAZ from 1 year post PEG. Patients who were deemed non-compliant with recommended regular use of the gastrostomy had a more marked decline in WAZ scores. The decline was significantly greater

in female compared with male patients. Failure to gain weight after gastrostomy was significantly associated with death within 2 years of the procedure (WAZ -2.5 ± 0.79 *vs*. -1.8 ± 0.84; *p*=0.007).

The mean FEV1 fell from 53.8% (SD ±14.21) at gastrostomy to 46.9% (SD ±19.34) in the following year. Patients with pathological GOR and oesophagitis had significantly lower weight-for-age z scores and FEV1. Mortality was associated with significantly lower FEV1 (57.3% ± 14.04 *vs.* 45.8% ± 11.56; *p*=0.015) at the time of gastrostomy. The average decline in FEV1[%] in the year after gastrostomy was 5.3% (SD 9.30). On regression analysis, the drop was less if FEV1 was higher at the time of surgery (*p*=0.04).

Conclusion: Mortality after gastrostomy in CF was associated with failure to achieve weight gain within 12 months and with lower baseline FEV1. Outcomes were worse in female patients, in patients who did not adhere to regular use of the gastrostomy and patients with symptomatic GOR or oesophagitis. Gastrostomies should be placed early before severe protein-energy malnutrition and end-stage lung disease are established. A prospective study is still ongoing.

Feeding refusal

A problem associated with long-term tube feeding is oral feeding aversion. Feeding aversion has profound effects on the parent-child interaction. Previous studies suggested that it can be difficult for a child to proceed to normal oral feeding after a prolonged period of tube feeding. Oral feeding can become aversive and the child resistant to resuming ordinary eating activity. As some of the children outgrow their medical condition such as short bowel syndrome, termination of HEN will hinge on achieving a sufficient oral intake to provide for growth and development.

This study examined the experience of prolonged enteral tube feeding for the pre-verbal child (aged 0-3) and their parents. Children between the ages of 0-3 years who have had a gastrostomy tube or a nasogastric tube in place for long-term feeding were recruited from medical and surgical units at the Royal Children's Hospital. Subjects received a developmentally based speech pathology treatment program which aimed at increasing their tolerance of oral experiences. They also received parent-child psychotherapy which was aimed at helping the infant and parents accommodate to the experience of tube feeding and subsequent attempts at oral feeding. Assessments were performed at enrolment and repeated at six months after the first intervention. The feeding and child psychiatric interventions were video taped and subject to a feeding interaction checklist and qualitative analysis.

Six children under 12 months of age were enrolled in the study. Recruitment of sufficient numbers of children who met the inclusion criteria proved difficult. This group of children who met the selection criteria was heterogeneous and had a wide range of medical and surgical conditions.

The children in the study demonstrated an improvement in developmentally appropriate feeding behaviour, and in five of the six cases tube feeding could be ceased. The interventions by the speech pathologist and child psychiatrist were accepted well by both parents and infants. Parents valued the non-stigmatising and non-conditional availability of the opportunity to discuss in detail their infant's

feeding problem, the primary medical problem and their own feelings about it. They also seemed to value the opportunity to talk about their experiences of the hospital and of other medical and nursing practitioners. Analysis and modeling of optimal feeding behaviour was well tolerated by both infant and parent. This study is ongoing.

Educational materials

A patient education booklet on gastrostomies has been developed at the Royal Children's Hospital. It has received excellent acceptance locally and nationally and has recently been revised for its second edition.

The Paediatric Nutrition Support Handbook has been developed to provide general practitioners and regional paediatricians with education on nutrition assessment, formulas and complications of tube feeding.

An Internet-based HEN education program is currently being developed. It contains a pictorial description of common problems and complications of gastrostomy tubes.

OUTCOMES ACHIEVED

We have:

1. Established best practice guidelines for the HEN in CP and CF
2. Established Victorian retrospective and prospective data which provides evidence to support the use of HEN in children with CP and CF
3. Established evidence to support the role of intervention to prevent and treat feeding aversion in children receiving HEN
4. Developed effective educational materials to support the use of HEN in community and regional areas. We have evaluated and modified these materials in response to these evaluations.
5. Presented the data in national and international scientific meetings. In addition the data is either published or being prepared for publication in international scientific journals
6. Prospective studies are continuing to establish the long-term clinical and economic outcome in children with CP and CF who receive HEN therapy.

Ongoing studies

The HEN Research initiative has provided the seeding funding for the initiation of important prospective studies into the clinical and economic outcomes related to HEN therapy in Victoria. Due to the short duration and the small numbers of patients enrolled in the prospective studies a complete cost benefit analysis could not be performed. This will be an important focus of the ongoing studies.

The following studies are still in progress:

1. Prospective CP cohort to assess the clinical and economic outcomes of HEN therapy in children with CP
2. Prospective CF study to assess factors that may predict outcome with HEN therapy
3. Prospective CF study to establish the economic outcome of HEN therapy in children with CF
4. Prospective CF study aimed at improving patient adherence with HEN
5. Prospective study continues to assess the parent-child interactional factors influencing success with oral feeding for infants receiving HEN

6. Continued development and assessment of the Internet-based HEN education program

SCIENTIFIC PRESENTATIONS AND PUBLICATIONS

Presentations

The research conducted as part of the this research initiative has been recognised nationally and internationally by acceptance for presentation to the following scientific meetings:

1. *MR Oliver, RG Heine, H Ng, E Volders, JR Thompson, A Olinsky:*
   Poster presentation (selected by organizers as poster of distinction)
   World Congress of Pediatric Gastroenterology, Hepatology and Nutrition, Boston, August 2000.

2. *JE Bines:*
   Home Enteral Nutrition - The future of nutrition support in paediatrics. Podium presentation, Grand Rounds, Royal Children's Hospital, 1999.

3. *SG Jimenez, AG Catto-Smith, MR Oliver, JE Bines, DJ Cameron, AL Smith:*
   Morbidity of percutaneous endoscopic gastrostomy at the Royal Children's Hospital. Podium presentation at the Australian Gastroenterology Week, Sydney, October 1998.

4. *JE Bines:*
   Future directions in Nutrition Support. Podium presentation at the Annual Conference of the Asia-Pacific Clinical Nutrition Society, Kuching, Malaysia, 1998.

Publications

1. JE Bines & A Mora-Guevara. Addressing the nutritional requirement of patients with cerebral palsy. *International Seminars in Paediatric Gastroenterology and Nutrition* 1999; 8(2):9-15.

2. MR Oliver, RG Heine, H Ng, E Volders, JR Thompson, A Olinsky. Factors affecting clinical outcome in gastrostomy-fed children with cystic fibrosis. (in preparation)

3. SG Jimenez, AG Catto-Smith, MR Oliver, JE Bines, DJ Cameron, AL Smith: Morbidity of percutaneous endoscopic gastrostomy. (in preparation)

4. RG Heine, V Dalton, R Bourke, DS Reddihough, AG Catto-Smith, JE Bines: Enteral feeding and nutritional rehabilitation in children with cerebral palsy. (in preparation)

5. O Saadah, RG Heine, V Dalton, R Bourke, AG Catto-Smith, MR Oliver, DS Reddihough & JE Bines. Gastro-oesophageal reflux and gastric emptying in tube-fed children with cerebral palsy. A prospective study. (in preparation)

6. L Ferguson & C Paul. Parent-child interactional factors influencing success with oral feeding programs for infants receiving enteral nutrition. (in preparation)

Best practice guidelines: HEN in Cerebral Palsy

1. Nutritional goals should be clearly defined.

2. The clinical response to Home Enteral Nutrition should be closely monitored, specifically with regard to weight gain and linear growth, and compared with age- and sex-related standards.

3. Evaluation for GOR disease before and after gastrostomy tube placement is required.

4. In children with severe GOR disease or evidence of pulmonary aspiration, a surgical anti-reflux procedure should be considered.

5. The cause of death in patients receiving HEN should be thoroughly and prospectively investigated in order to determine if there is any direct or indirect relationship with HEN delivery or with the gastrostomy tube.

Best Practice Guidelines: HEN in Cystic Fibrosis

1. Gastrostomy tubes should be placed prior to the onset of severe protein-energy malnutrition or severe lung dysfunction. This appears to be particularly important in females with CF.

2. Prior to placement of a gastrostomy, patients should be carefully assessed for factors that may affect adherence to gastrostomy tube use.

3. Symptomatic GOR should be rigorously treated as it may adversely affect pulmonary function and clinical outcome.

4. If patients fail to achieve their nutritional goals within 3 to 6 months after gastrostomy placement, several additional nutritional interventions should be considered. These should include commencement of elemental feeds and use of agents that improve the bioavailability of pancreatic enzymes.

5. Input from a clinical psychologist prior to gastrostomy placement may be of benefit in reducing barriers to gastrostomy placement by addressing issues of body image, especially in females with CF. Patients and their families should be motivated to adhere to the prescribed treatment.

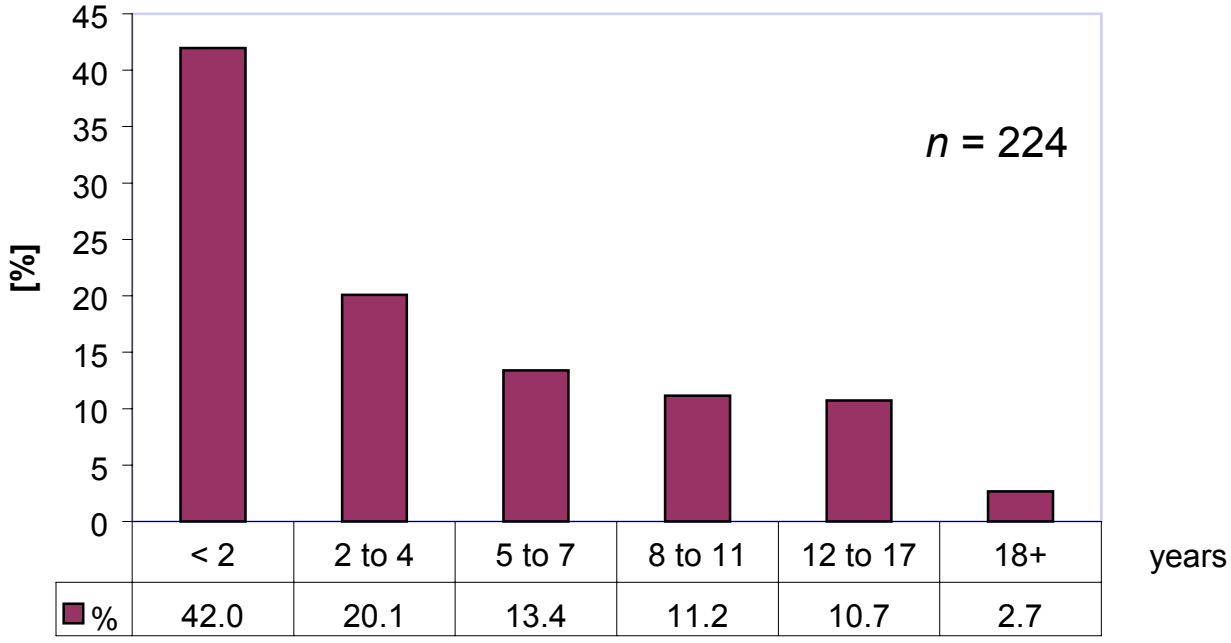
PROVISION OF ENTERAL NUTRITION AT THE ROYAL CHILDREN'S HOSPITAL

Investigators:

RG Heine, V Dalton, L Rogers, AG Catto-Smith, JE Bines

In 1999, between 220 and 250 patients received Home Enteral Nutrition (HEN). The majority of patients were tube-fed for longer than 6 months. A small group of patients only required temporary nutritional report, e.g. after intensive chemotherapy or due to an intercurrent illness. On a representative day (27 October 1999), 224 patients received HEN. Of these, 126 (56.3%) were male, and 98 (43.7%) were female. The mean age of this group was 7.6 years (SD ± 5.94; range 0.1 to 24.0 years; median 6.1 years). The largest group was made up of infants under 2 years (42.0%), and about 2/3 were under 4 years of age.

Figure 1: Age range of HEN patients (date 27/10/99)



The spectrum of diseases included virtually all clinical subspecialties. Table 1 summarises the range of medical conditions.

Table 1: Primary medical conditions in children requiring HEN

Condition	Number of patients	%
Cerebral palsy, neurological impairment, intellectual disability and developmental delay	120	53.5
Gastrointestinal disorders, including short bowel syndrome	28	12.5
Cystic fibrosis	19	8.5
Malignant neoplasms	15	6.6
Renal disease, including chronic renal failure	14	6.2
Metabolic disorders	13	5.7
Premature infants	9	4.0
Congenital heart disease	7	3.1
TOTAL	**224**	**100**

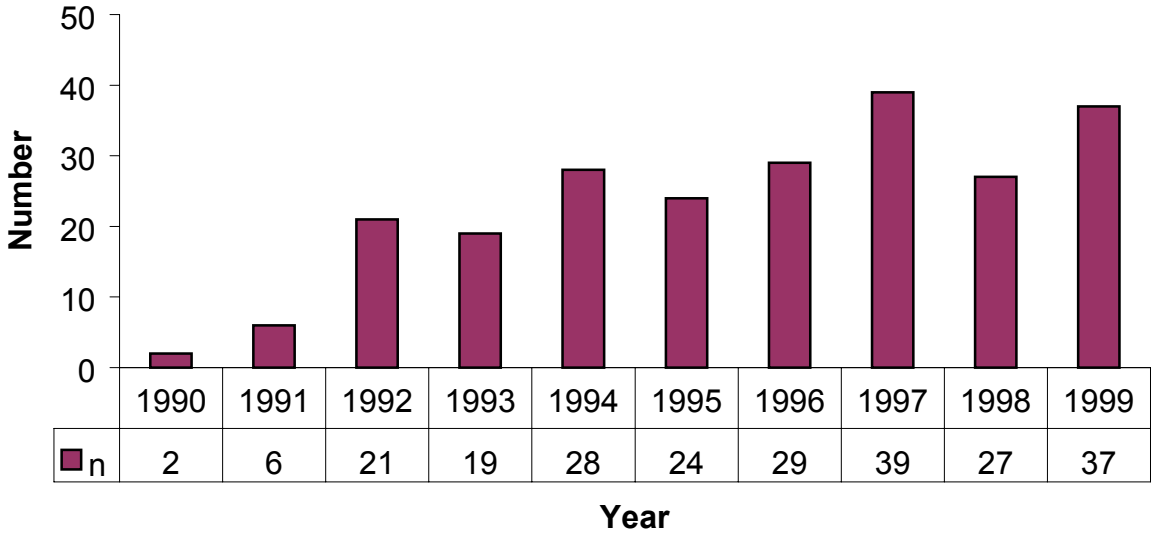
PERCUTANEOUS ENDOSCOPIC GASTROSTOMIES – A retrospective review of indications and outcomes

Investigators*:*
S Jimenez, RG Heine & AG Catto-Smith

Until recently, feeding gastrostomies had to be placed surgically. The need for a laparotomy was associated with significant morbidity, particularly in patients with long-standing protein-energy malnutrition. In 1980, Gauderer and Ponsky (1,2) described a method of an endoscopically placed gastrostomy (Percutaneous Endoscopic Gastrostomy; PEG). The technique was subsequently modified for routine clinical practice in children and adults (3-7). It has proved to be a safe procedure and is associated with a lower morbidity and mortality compared with conventional surgical gastrostomies. It also appears to be more cost effective in view of the shorter procedure time and hospital stay. This technique was first used at the Royal Children's Hospital in 1990.

We retrospectively reviewed the indications and outcome of all patients who underwent PEG placement between 1990 and 1999. During this 8-year period, a total of 232 PEG were placed. The number of PEG procedures has increased significantly since its introduction in 1990. This trend appears to have stabilised over the last years of the study with about 30 – 40 new PEG placements annually (Table 2).

Figure 2: Number of PEG procedures between 1990 – 1999

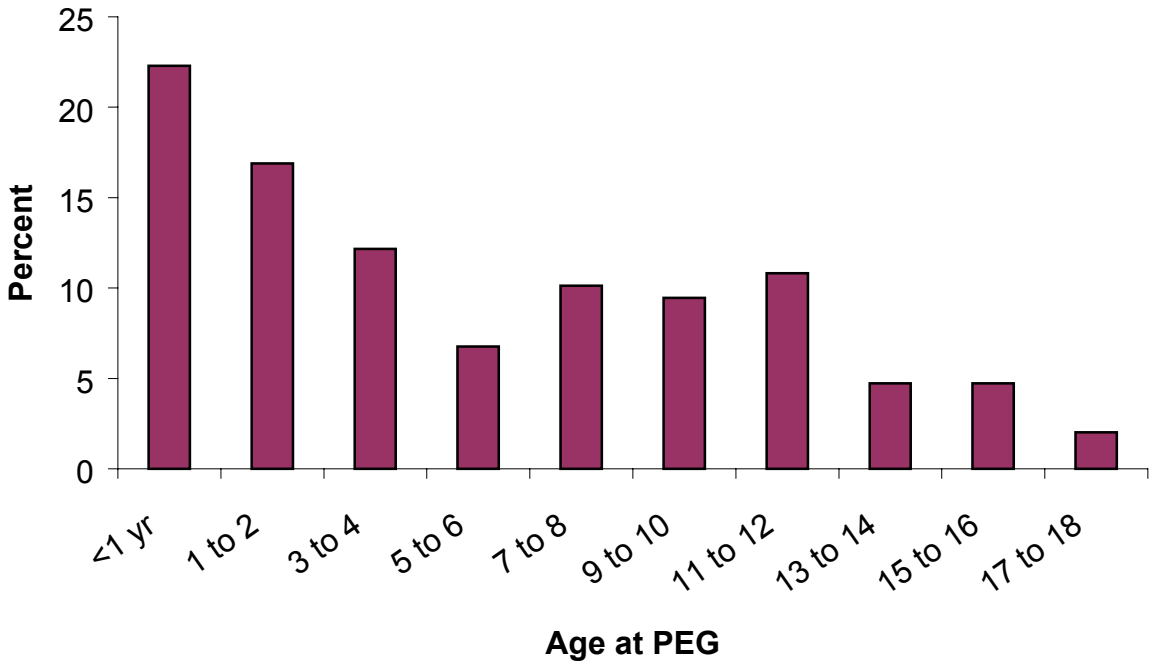


Patient profile

The mean age at placement of the PEG tube was 5.9 years. The youngest patient was a 43-day-old infant with CP secondary to neonatal asphyxia. The oldest patient was a 20-year-old man with spinal muscular atrophy.

Twenty-one percent of patients were below one year of age when the PEG was placed. Nineteen percent had undergone previous abdominal surgery. Seven percent of patients required fundoplication before, and ten percent after PEG placement. Figure 3 summarises the age distribution at PEG placement.

Figure 3: Age at PEG placement



Indications

PEG were most commonly placed in children with malnutrition due to severe swallowing difficulties and dysphagia. Fifty-six percent of patients had a PEG tube inserted for treatment of feeding difficulties in association with swallowing abnormalities. The majority of these patients had neurological impairment, mainly CP, or multiple congenital abnormalities.

In 40% of patients a PEG tube was used for supplementary feeding to improve the nutritional status of patients with underlying chronic disease and protein-energy malnutrition. This included patients with CF, renal disease, cardiac disease or gastrointestinal conditions. In 4% of patients the gastrostomy tube was placed for other than nutritional reasons. This included tube placement for long-term administration of bowel washouts in patients with severe intestinal dysmotility or severe chronic idiopathic constipation.

Mortality

Just under a quarter of PEG patients died within the 8-year study period. The majority of these patients had severe neurological impairment / CP. The most common cause of death was pneumonia. This was suspected to be associated with aspiration in 19% of these patients. Forty-five percent had no identifiable cause of death. One patient with a chromosomal abnormality died 7 days after insertion of the PEG tube as a result of cardiac failure which was unrelated to the surgical procedure. One patient died 8 months after PEG placement because of relapsed acute myeloid leukaemia.

Duration of PEG feeding

The majority of patients used their PEG tube from the time of insertion to the completion of the study. Only 10% had their gastrostomy tube removed because it was no longer required. The duration of PEG feeding in those who had the tube removed during the study period was 18 months.

Gastrostomy tube replacement

In 151 patients, between 1990-1997, a total of 287 gastrostomy replacement procedures were performed. Ninety-two (32%) of replacements were done during hospital admissions for tube-related or unrelated problems. Over half of gastrostomy tube replacements, 151 (53%), were done on an outpatient basis.

Table 4: Replacement Tubes

Type of tube	Number	%
Balloon gastrostomy tube (MIC)	98	34.1
Low-profile balloon device	75	26.1
Bard low-profile device (‘button”)	64	22.3
Other	11	3.8
Unknown	39	13.6

Balloon gastrostomy tubes were the most common replacement devices which were used in 98 (34%) of patients after removal of the initial PEG tube. Low-profile button gastrostomy devices (Bard® 'button') were used in 64 (22.3%) of the patients. The lifespan of the tubes differed considerably between types. The MIC balloon gastrostomy tubes usually lasted about 3 months. In contrast, the low-profile Bard® 'button' lasted in most cases for more than 12 months. The low-profile balloon device (MICkey) generally lasted between 1 and 6 months with a large variability between patients (Tables 5 and 6).

Table 5: Duration of initial tubes before replacements

Duration	Number	%
1-3mos	36	31.6
4-6mos	28	24.6
7-9mos	13	11.4
10-12mos	8	7.0
>1 year	23	20.2
Unknown	6	5.3

Table 6: Lifespan of replacement gastrostomy devices

Duration	MIC balloon gastrostomy tube	Low-profile balloon device (MICkey)	Low-profile device (Bard® 'button')
< 1 week	10	3	4
1-3 mos	28	9	6
4-6 mos	20	9	7
7-9 mos	4	0	2
10-12 mos	4	2	3
> 1 year	11	5	16
unknown	21	21	23
not applicable	0	0	3

Conclusion

- Gastrostomies have become an integral part in the provision of HEN in patients with chronic disorders and complex nutritional needs. Over the past 8 years there has been a significant increase in the number of PEG tube placements and subsequent replacement procedures.

- Replacement of gastrostomy tubes is an important logistic and financial problem, and this study has highlighted the importance of ongoing review of the cost/duration ratios or different devices. Facilities for the safe replacement and monitoring of these tubes are an important part of the HEN Service.

- The relatively high mortality seen in patients receiving HEN reflected their medical complexity and underlying medical conditions. It is generally accepted that the mortality rate of children with severe CP is of a similar magnitude. Complications directly attributable to gastrostomy tube placement were infrequent.

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CEREBRAL PALSY

HOME ENTERAL NUTRITION IN CHILDREN WITH CEREBRAL PALSY – An overview

About 1500 children with cerebral palsy (CP) are currently being managed at the Royal Children's Hospital, about one third of them being severely affected. Many of these children are malnourished as a consequence of disordered swallowing and poor oral intake. Feeding may take up to several hours per day, which causes stress and frustration for both patients and caregivers. An increasing proportion of these patients therefore depend on long-term HEN.

Nutritional issues present an enormous challenge to the medical and nursing staff and the families caring for children with CP. Malnutrition and growth failure are well recognised problems in children with spastic quadriplegia (1,2). In addition, between 20 to 30% of children with diplegia and hemiplegic CP are underweight for age or stunted and obesity is reported in 8-14% (3). Despite this high incidence of malnutrition, the extent of malnutrition in this population often goes unrecognised or inadequately treated. This is often blamed on the difficulty in clinically assessing growth as result of physical deformity from scoliosis, joint contractures, muscle atrophy and movement disorders. There are also complex legal and ethical considerations as well as practical aspects such as jeopardizing the ability of a parent to independently carry their child if treatment results in excessive weight gain. Over the past decade it has become increasingly obvious that the high incidence of malnutrition in patients with CP reflects aberrations in food intake, physical activity, physical stature and body composition and that nutritional recommendations developed from healthy populations are not appropriate for use in patients with CP (1).

Accurate assessment of the nutritional requirements of children with CP potentially has a direct clinical benefit for these children. Energy and protein deficits may restrict growth, impair cognitive development and neuromuscular function. An important cause of death in children with CP is chest infection. Poor nutritional status has been shown to significantly impair the body's ability to

fight infection and therefore may contribute to mortality. With nutritional rehabilitation, children with CP have demonstrated improved weight gain, subcutaneous fat stores and muscle mass (4). These nutritional parameters have also been accompanied by functional improvement such as decreased irritability and spasticity, improved peripheral circulation and healing rate of decubitus ulcers (4,5,6). While many of these children have a restricted life experience due to their disability, increased strength and feeling of well-being due to improved nutritional status may enhance their ability to participate more fully in a variety of activities.

It is also important not to overfeed children with CP. Children with severe disability often have problems with GOR and regurgitation placing them at risk of aspiration and chest infection. Increasing the volume of feed may result in gastric distension potentially contributing to this risk. Children with mild to moderate disability who require aids for walking may have the same food intake as their fully ambulatory peers but may be less physically active. As a result obesity is not uncommon in this group. Obesity makes it harder for these children to ambulate, and they are at increased risk of instability and falls when using their walking aids.

Why children with cerebral palsy are at risk for malnutrition

The cause of malnutrition in children with CP is multi-factorial. It may result from insufficient food intake, feeding problems, increased nutrient losses due to vomiting or interaction with medications and alteration in energy requirements due to increased muscle tone or involuntary muscle movement (Table 1).

Table 1: Etiology of Malnutrition and Growth Failure in Children with CP

1. Feeding Problems

a. Mechanical problems
- Lack of independent feeding skills
- Spillage

b. Functional abnormalities
- Oro-motor dysfunction
- Poor dentition, oral cavities
- Swallowing disorders
- Inadequate lip closure
- Salivation or drooling
- Extrusion reflex
- Tonic bite reflex
- Tongue incoordination
- Gagging, coughing, choking
- Delayed swallowing
- Vomiting / gastro-oesophageal reflux
- Dysphagia
- Oesophagitis
- Abdominal distension, aerophagia
- Constipation

c. Behavioural problems

d. Medications
- Drowsiness
- Altered taste or appetite

2. **Nutrient losses**

a. Mechanical problems
- Spillage
- Regurgitation

b. Gastrointestinal losses
- Vomiting
- Diarrhoea
- Malabsorption

c. Drug-nutrient interactions

3. Metabolic or Hormonal Disorders

a. Metabolic
- Altered metabolic rate
- Immobility
- Seizures
- Infection

b. Hormonal
- Thyroid hormone abnormalities
- Growth hormone deficiency

One of the most important day-to-day issues facing children with CP and their families is centred around feeding and food. It can be a source of frustration and guilt in caregivers and due to the time invested in feeding, this may become a major focus of the family's daily activities. Approximately 33% of children with CP have oro-motor dysfunction, and 25% of this group have moderately or severely impaired self-feeding skills (7). Feeding problems may result from motor problems including hypotonia, poor head control, weak or absent suck reflex, poor hand to mouth coordination, poor lip closure, poor coordination of the swallowing mechanism, tonic bite reflex, hyperactive gag reflex, and exaggerated tongue thrust and inability to self feed. Children with CP who require assistance with feeding have a significantly lower mean z score for weight and height compared to CP children who do not require assistance (personal data).

Vomiting or regurgitation is an important cause of nutrient loss in some children with CP. Alternative approaches to oral feeding such as naso-gastric or gastrostomy tube feeding may exacerbate reflux and regurgitation and therefore management of reflux must be linked with nutritional intervention in those patients with pre-existing reflux.

Predisposing factors leading to nutritional disorders

Intrauterine and post-partum events which may result in the development of CP may also be an important cause of poor growth and an independent risk factor for nutritional deficiency. Prematurity and intrauterine growth retardation are risk factors for malnutrition and growth abnormalities in children with CP. The incidence of major disability varies from 5 to 10% for infants with a birth weight below 1500g and up to 20% for infants with a birth weight below 1000g (Table 2). Very low birth weight infants are at significant risk for the development of chronic lung disease, intraventricular haemorrhage, retinopathy of prematurity, hearing impairment, and failure to thrive, and they are more likely to require intensive support including mechanical ventilation and parenteral nutrition. Follow-up of low birth weight infants demonstrates linear stunting and poor weight gain at 4 to 5 years of age. Approximately 22% of infants with CP had low birth weight at delivery. Intrauterine growth retardation may result from a chromosomal disorder

or congenital which are often associated with severe central nervous system malformations and poor growth. Maternal medications, such as phenytoin, drug or alcohol abuse and environmental toxins may impair foetal growth, cause congenital malformations or dysmorphic features, and may damage the central nervous system.

Table 2: Predisposing Factors For The Development Of Nutritional Disorders In Children With Cerebral Palsy

1. Prematurity
2. Characteristics of the neurological disorder
    - Aetiology
    - Multiple malformations
    - Multiple disabilities
    - Severe involvement
    - Prolonged duration
3. Primary oro-motor dysfunction
    - Swallowing disorders
4. Associated gastrointestinal disorders
    - Gastro-oesophageal reflux
    - Oesophagitis and/or Gastritis
    - Constipation
    - Malabsorption

Nutritional requirements

Despite the scope of nutritional problems in children with CP there is limited scientific data to base nutritional recommendations in this population. At present, recommended age-specific energy requirements for children with children with CP are generally based on those developed from the neurologically intact, normal children. Early studies of energy requirements in children with CP defined energy needs in terms of dietary intake required for patients to remain weight neutral. The excessive amounts of energy intakes per unit body mass or height reported in these early studies resulted in the impression that patients with CP had increased energy expenditure. However, it has been demonstrated that dietary intake data in this population significantly over estimates energy intake by about 44-54% due to losses from spillage, vomiting and regurgitation (8). More recently, Bandini *et al*. studied body composition, resting energy expenditure and total energy expenditure in 13 adolescents with CP using a combination of indirect calorimetry and the doubly labelled water method (9). In this study resting and total energy expenditure were significantly reduced in non-ambulatory patients. However, due to the relatively small number of the patients in this study the effect of the type of disability and abnormal muscle movements on energy expenditure could not be elucidated. Stallings *et al.* studied dietary intake, body composition and energy expenditure in 61 children aged 2-18 years with spastic quadriplegic CP and a normal control group (8). The energy expenditure of children with spastic quadriplegic CP was reduced in all energy compartments measured (resting energy expenditure, physical activity, total energy expenditure) when compared to normal controls. The total energy expenditure of spastic quadriplegic CP patients was significantly lower than the control group when expressed as kJ/d, kJ/kgbodywt·d, kJ/kgFFM·d or as a percentage of the recommended daily allowance as kJ/d. Energy for non-basal needs, as reflected by the ratio of total energy expenditure to resting energy expenditure was significantly lower for the spastic quadriplegic CP group compared with controls with the lowest ratio found in the poorly nourished CP group. These data suggest that energy expenditure is not increased in spastic quadriplegic CP and that nutritional deficiency is a result of inadequate nutrient intake. This conclusion is supported by a study of the energy intake of a group of children and

adolescents with spastic quadriplegic CP fed exclusively by gastrostomy tube (10). These patients grew well receiving energy intakes lower than he recommended dietary allowance for age. Protein requirements of children with CP should be based on RDA for age and sex in the absence of disease-specific guidelines for CP.

A normal diet of a variety of meat, fruit and vegetables will provide the essential macro- and micronutrients for growth and development. However, due to the nature of the feeding difficulties in CP and limited ability to develop food preferences and experiences, dietary intake may be restricted in variety.. The absorption of some oral medications can be influenced by the food present in the gastrointestinal tract. On the other hand, medications and drugs can affect the synthesis, absorption, distribution, and excretion of nutrients (Table 3) (11).

Assessment of nutritional status

The failure to recognise and treat malnutrition in patients with CP is often blamed on the problems in assessing nutritional status in these patients. Scoliosis, spasticity and joint contractures make routine measures of linear growth notoriously inaccurate. There are also disturbances in the distribution of fat stores between the limbs and trunk and even between sides of the body when asymmetry is present. However, with consideration of a patient's individual neuromuscular problems, reliable measurement of linear growth and body composition can be obtained. Clearly the determination of these parameters are pivotal to identify patients at risk of malnutrition and monitor the response to nutritional intervention. A guide to the approach to the nutritional assessment of a patient with CP is outlined in Table 4.

The dietary assessment should not only document the nutritional integrity and variety but also assess feeding skills. An understanding of the events surrounding mealtime is also important including who feeds the child, when, how, how long does it take and what happens in the event of a problem such as regurgitation. A detailed medical history may give important clues to underlying medical problems that may also influence growth expectations such as extreme

prematurity. Neuromuscular problems, extent of physical disability and orthopaedic complications including prolonged periods of immobilization may influence aspects of nutritional status and bone mineral density. Medications may interfere with nutrient absorption or alter the metabolism of specific nutrients.

Weight is the most universally available measure of nutritional status. Weight can be plotted on charts developed from normal children of the same sex and age. Weight for height is useful for ambulatory patients or patients with minimal spine deformities or joint contractures.

Measurements of linear growth are easily and reliably obtained from ambulatory patients with no joint deformities using a stadiometer. However, patients with scoliosis, spasticity or joint contractures require an alternative approach. The measurement of upper arm length and lower leg length has been shown to be an accurate and reproducible measurement of linear growth in patients with spastic quadriplegia, diplegia and hemiplegia (1,2,3). The measurement of lower leg length can be performed without an anthropometer and therefore can be performed in any clinical environment. Stallings *et al*. in 1993 reported that nutritional status accounted for 10 to 15% of the variation in linear growth in a group of children with spastic quadriplegic CP after consideration of disease severity and other factors such age and sex (2). This effect was maximal in the younger patients. Even in the less severely affected patients with diplegia and hemiplegia a reduction in linear growth is detected. Longitudinal assessment of linear growth enables the determination of growth velocity. This is valuable in evaluating the effect of clinical interventions on growth. Children with CP have been reported to have slower linear growth rates compared to age and sex-based standard values which indicate the influence both disease-related and nutritional factors on linear growth (12).

Basic anthropometric techniques including mid-arm circumference and four site skin-fold thickness measurements (triceps, biceps, subscapular, suprailiac) are easily performed in the clinic and, if performed by an experienced technician,

provide reliable body composition data. Patients with spastic quadriplegic CP have reduced fat stores with a greater reduction in triceps compared with subscapular sites (1,2). Stallings *et al.* suggested using the Slaughter 2 skin-fold prediction equation to estimate percentage body fat in prepubertal children with CP (13). However this approach was not substantiated by a recent study by van der Berg-Emons et al (14).

Arm muscle area appears to be preserved in patients with spastic quadriplegia, hemiplegia and diplegia. However, this may reflect disease factors such as distorted arm shape, spasticity or simply an artifact of depleted triceps fat stores or bone size.

The wider availability of other methods of body composition assessment including total body potassium measurement and dual energy x-ray absorptiometry provides a useful adjunct to nutritional assessment in the cooperative patient. Currently bioelectrical impedance analysis has limited value due to body asymmetry as a result of scoliosis and contractures. With further development, segmental bioelectrical impedance may become a useful bedside tool to assess body composition in this patient population.

Indirect calorimetry provides a measurement of resting energy expenditure which may assist in developing energy goals for nutritional intervention. It is a simple technique but requires the patient to lie still for the 30 to 60 minute period during the measurement. Measurements of total energy expenditure using heart rate monitoring and the doubly labelled water technique are generally limited to the research setting.

Serial measurements of serum nutritional markers are required to provide a global nutritional assessment. Disturbances of bone mineralisation are well recognised in patients with CP and may include osteopenia, stunting and fractures. Patients with spastic quadriplegic CP are at risk of metabolic bone disease due to immobility, orthopaedic procedures such as hip-spica casts and surgical interventions, anticonvulsant medications, prematurity and malnutrition. The dual energy x-ray absorptiometry method is a measurement of bone mineral density and assists in the diagnosis and monitoring of metabolic bone disease (15).

Micronutrient deficiency in cerebral palsy

Protein energy malnutrition observed in patients with CP is usually accompanied by disturbances in micronutrient status. This reflects the inadequacy in the quantity and quality of nutrition provided. Disturbances in micronutrient status should also be considered in patients with limited variety in the diet even if the energy intake appears to be adequate. Total body depletion of the essential nutrients calcium, phosphate, magnesium, iron and zinc are frequently encountered. These may become obvious during re-feeding when intracellular shifts of potassium, phosphate and magnesium can cause life-threatening arrhythmias. Deficiencies in zinc and vitamin C may contribute to poor wound healing and resistant decubitus ulcers.

The absorption and activity of some oral medications can be influenced by the food present in the gastrointestinal tract. In addition, medications can affect the synthesis, absorption, distribution, and excretion of some nutrients (Table 3) (11).

Children receiving medications known to have these interactions should have annual serum micronutrient to assess the need for a specific nutrient supplement.

Selecting the appropriate route

The selection of the most appropriate route for the provision of nutritional therapy is based on a number of individual patient-related factors. These include the type and severity of the disability and associated complications, the goal of therapy, the anticipated duration of therapy and important social considerations which may affect the ability of caregivers to safely and effectively administer enteral nutrition via a tube. Once the need for nutritional intervention has been established, a limited trial of supplementation of oral feed with energy dense foods, increased diversity of foods, specific nutritional supplements and alterations to the feeding regimen may be appropriate. With frequent review and modification to the program some patients may obtain benefit and avoid tube-based protocols. Despite the use of oro-motor stimulation for long periods of time many children with severe neurological disabilities do not achieve minimal standards of growth with oral feeding alone. These children spill a significant proportion of their food, cannot chew or swallow solids and may have difficulty drinking or using a straw. Children with CP can take two to eighteen times longer than controls to chew and swallow a standard amount of pureed food and one to fifteen times longer for solid food. As a result some caregivers spend up to seven hours per day feeding their children. It has been suggested children with CP should be weaned from pureed to solid food to stimulate chewing skills. While some patients gradually learn to chew many have continued difficulty. For these patients tube feeding is necessary to prevent or treat malnutrition and improve the quality of life for their families.

Table 3: Assessment of nutritional status

1. Dietary and Feeding History

2. Medical History including neurological manifestations medications, orthopaedic complications, mobility

3. Growth and body composition
   (i) Weight
   - weight for age/sex
   - weight for height
   - z score

   (ii) Linear growth
   - Ambulatory patients - Standing height using stadiometer
   - Non-ambulatory patients without significant scoliosis or spasticity
     - recumbent length using supine measuring table
   - Non-ambulatory with scoliosis, spasticity or contractures
     - upper arm length (acromion-radial length)
     - lower leg length (tibial-sphyrion length)
   - Growth velocity - for age/sex

   (iii) Body composition
   - Anthropometry
     - mid upper arm circumference
     - skin-fold thickness
   - Total body potassium measurement
   - Total body nitrogen measurement
   - Segmental bioelectrical impedance
   - Total body water analysis by D_2O dilution method
   - Dual energy X-ray absorptiometry

4. Measurement of energy expenditure
   - Resting energy expenditure by indirect calorimetry
   - Total energy expenditure by the doubly labelled water technique
   - Heart rate monitoring

5. Serum measures of nutritional status
   - full blood examination
   - electrolytes
   - serum albumin, total protein
   - Ca, Mg, PO_4, zinc
   - Vitamins A, D, E, PT
   - iron, ferritin, vitamin B_{12}, folate

6. Bone-mineral density
   - Dual energy X-ray absorptiometry
   - Generally restricted to research protocol

Naso-gastric tubes have the advantage of being easily placed and replaced, require no surgical intervention for placement and are relatively inexpensive. However they are associated with complications such as otitis media, sinusitis, tube misplacement or dislodgement and an increase in vomiting or GOR with the potential risk for aspiration. Naso-gastric tube feeding should be considered for patients requiring short-term therapy or who have a medical or surgical contra-indication for gastrostomy tube placement.

When long-term tube feeding is indicated (months to years), placement of a gastrostomy tube should be considered. The percutaneous endoscopic gastrostomy (PEG) tube placement method has a number of advantages over the open surgical technique. It is quick to perform which limits anaesthetic duration, is associated with less post-operative discomfort which may reduce lung complications and can be used immediately after placement. The combination of plication of the surface of the stomach to the anterior abdominal wall altering gastric mechanics as well as gastric distension with feeds in patients with pre-existing disturbed oesophago-gastric motility may explain to the increase in GOR noted in patients with spastic quadriplegic CP post-gastrostomy tube placement. Many centres now recommend investigation for potential GOR in all patients with CP prior to performing a gastrostomy. This includes oesophageal 24-hour pH monitoring, gastric emptying nuclear scan, oesophageal manometry and oesophageal biopsy. Patients with significant GOR and no features of oro-pharyngeal or oesophageal dysmotility should be considered for fundoplication in association with gastrostomy tube placed which could be performed as a single surgical procedure. Fundoplication may create an increased risk of aspiration of swallowed oral secretions pooling in the lower oesophagus above the plication. The relative risk versus benefits of fundoplication can only be assessed on an individual patient basis.

Jejunal feeding either by naso-jejunal, gastro-jejunal or jejunal tube has the potential advantage of infusing relatively large volumes of feed distally with reduced risk of aspiration. Dislodgement is a significant problem with naso-jejunal and gastro-jejunal tubes as the tube tip is in the proximal jejunum.

However, as equipment and techniques for placement of these tubes improve they will provide an important alternative to gastric feeding.

Selecting the right formula

In patients with no underlying gastrointestinal disease or food sensitivity a standard polymeric diet with a cow milk based complete formula is appropriate for naso-gastric and gastrostomy tube feeding. There is a wide range of commercial formulas available. The decision on which formula is appropriate for a specific patient depends on patient age, fluid requirements or restriction and associated medical problems such as lactose intolerance or constipation. Patients less than 2 years of age may be managed with a standard cow milk based infant complete infant formula such as S26, SMA, Enfalac or Nan 1. Children over 2 years can safely be given adult formulas, however, a number of child specific formulas such as PediaSure and Peptamen Jr provide a nutrient profile specially developed for the growing child. Commonly available adult polymeric formulas include 1kcal/ml formulas (for example Ensure, Isocal, Nutren 1.0, Isosource), 1.5 kcal/ml formulas (for example Resource Plus, Ensure Plus, Sustagen Plus, Comply, Nutren 1.5) and 2 kcal/ml formulas (for example Twocal, Nutren 2.0, Deliver 2.0). For patients with significant constipation a fibre supplemented formula may be helpful (for example Jevity, Sustacal with fibre, Ultracal, Compleat, PediaSure with Fiber). Patients with diarrhoea should be evaluated with a stool analysis to assist with formula selection. A stool pH<4 with reducing substances greater than 1% suggests lactose intolerance and the patient may benefit from a lactose free formula (Isocal, Osmolite). An isotonic formula (for example Osmolite, Isocal) or a fibre enriched formula such as Jevity may help control diarrhoea in some patients. As jejunal tubes infuse formula more distally, a semi-elemental formula (for example Pregestimil, Vital) or elemental formula (for example Vivonex Pediatric, Neocate or Elemental 028) is recommended.

Feeding regimens

Formula can be delivered via a naso-gastric or gastrostomy tube by bolus, drip or pump infusion. Bolus feeds are usually given using a syringe and the volume and frequency of feed vary according to the patient's age and medical condition. Bolus feeds are generally preferred as they have minimal impact on physical activity, are simple to administer and require minimal equipment. Families also prefer bolus feeds as they provide a social equivalent to a meal and can be incorporated in to the family's activities.

Drip feeds are generally used in patients who cannot tolerate the more rapid instillation of formula which occurs during a bolus feed. The rate of infusion can be titrated to the patient's response. Continuous infusion of formula via an enteral feeding pump can accurately infuse small volumes of formula to patients who cannot tolerate bolus or drip feeds. Overnight continuous enteral infusion provides an opportunity to maximise nutrition in patients who are physically active during the day but cannot tolerate bolus feeds. The combination of oral diet, bolus feeds and supplementary overnight enteral infusion works well for some patients and their families. Continuous infusion is required for patients with jejunal tube feeding. This can be infused over the day or night only in patients who are physically active.

Monitoring

After a naso-gastric or gastrostomy tube has been inserted in a chronic malnourished patient care should be taken to obtain nutritional goals gradually. In the enthusiasm to correct the nutritional deficit these patients may be placed at risk of developing metabolic complications associated with the re-feeding syndrome. Patients at highest risk have a history of chronic malnutrition, an acute weight loss of 10-20%, prolonged fasting or minimal intake for the preceding 7-10 days (less in younger children). Re-feeding syndrome occurs generally in the first 3-5 days after the initiation of adequate nutrition and can be identified by the development of hypokalaemia, hypomagnesaemia, hypophosphataemia and hyponatraemia. If these electrolyte disturbances are allowed to go untreated patients are at risk of developing life-threatening

complications including cardiac arrhythmia, cardiac failure and seizures. Re-feeding syndrome can be prevented by identifying patients at risk and initiating feeds gradually over the first 3 to 5 days of nutritional therapy. Serum electrolytes, calcium, magnesium and phosphate should be measured daily for the first 5 days of therapy and deficiencies promptly corrected. Regular monitoring of patients receiving nutritional intervention is the key to a successful clinical outcome. All too often a gastrostomy tube is placed and enteral feeding commenced without adequate review to ensure that the nutrition provided is tolerated. Patients receiving enteral nutrition should be reviewed at least 3 monthly initially and 6 monthly thereafter.

A multidisciplinary team approach to the management of HEN provides a comprehensive service to patient and their families and caregivers (16). This team includes a physician/surgeon, dietitian, nurse practitioner, stomal therapist, and often also a speech therapist and social worker. The patient and caregiver should be provided with written educational material and documentation of the tube in situ and replacement details. A 24 hour contact telephone number or facility should be available to the caregiver so they can obtain assistance in the event of a complication or tube failure.

Conclusion

Identifying nutritional deficiencies and providing appropriate nutritional intervention for patients with CP has the potential to enhance growth and reduce complications related to poor nutritional status. Patients are provided the opportunity to maximise their functional capabilities and improve their quality of life and the quality of life of their family.

Table 4: Monitoring of patients with cerebral palsy receiving HEN

1. Dietary History
2. Medical History including medication
3. Assessment of Nutritional Status
   - weight
   - linear growth
     - recumbent length
     - standing height
     - upper arm length, lower leg length
     - growth velocity
   - body composition
     - Mid arm circumference
     - Triceps/biceps/subscapular/suprailiac skinfold thickness
   - serum nutritional markers (12-monthly)
     - U & E, Ca, P, Mg, albumin

     (micronutrients as indicated)

4. Assessment of feeding method
   - Integrity of tubing and equipment
   - Review care of tubing and equipment
   - Stoma
   - Feeding regimen

5. Review of complications
   - Diarrhoea/constipation
   - Stomal problems
   - Vomiting

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HOME ENTERAL NUTRITION IN CHILDREN WITH CEREBRAL PALSY - A retrospective review at the RCH from 1990-1997

Investigators

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Background

Cerebral palsy (CP) is a non-progressive condition of the central nervous system that is caused by a variety of diseases during pregnancy or by birth asphyxia. It is the most common cause of disability in childhood. Children with CP are often malnourished as a consequence of disordered swallowing and poor oral intake. Feeding may take up to several hours per day, and choking episodes and hypoxia are common [1]. A large proportion of these patients rely on long-term home enteral nutrition (HEN). Since 1990, endoscopically placed feeding gastrostomies have been introduced into clinical practice and have started to replace nasogastric tubes.

Feeding gastrostomies are generally considered a safe route of delivering enteral nutrition. Besides their advantages there are, however, potential hazards that need to be addressed. Children with CP have a high incidence of GOR [2] which is worsened in about 25% of patients after gastrostomy placement [1]. Regurgitative reflux may result in aspiration of gastric contents into the lungs causing chronic pneumonia or even death. No reliable clinical predictors of an increase in reflux have so far been identified. Some clinicians therefore advocate performing a surgical antireflux procedure (fundoplication) in conjunction with gastrostomy placement. This remains an area of controversy [3]. It has been our practice over the past few years to place percutaneous endoscopic gastrostomies (PEG) without antireflux surgery [4] but to perform a fundoplication later if there is evidence of increased reflux.

The aims of the present study were:

1. To review the use of surgical and endoscopic gastrostomies in children with CP in the years 1990-1997 at RCH
2. To review the use of long-term nasogastric tubes in the same population
3. To outline the complications associated with gastrostomy placement
4. To outline the use of surgical gastrostomy with fundoplication versus endoscopically placed gastrostomy
5. To review health outcomes after gastrostomy placement with particular emphasis on nutritional status, lung disease, hospitalisation rates and mortality
6. To review cost effectiveness of gastrostomy placement
7. To assess nutritional outcomes

Methods

This study was a retrospective chart review of all patients with CP who underwent endoscopic or surgical gastrostomy at the Royal Children's Hospital during an 8 year period from 1990 to 1997. Charts were reviewed by a paediatric gastroenterologist (RH,JB) and a paediatric dietitian (RB,VD) and data collected on a 5 page standardised questionnaire developed for this study. Data was then collated onto a computerised database program (Microsoft Excel) for analysis.

The following data were included for analysis:

1. Patient demographic data
2. Medical history
3. Dietary history
4. Patient growth and weight gain data pre- and post gastrostomy placement
5. Gastrostomy placement details
   Date of insertion, Type of insertion
   Association with a fundoplication procedure
6. Enteral feeding regimen
   Nutritional requirement , % estimated energy requirement provided

by HEN, trial of naso-gastric feeding prior to gastrostomy tube placement, feeding method, formula used, oral intake

7. Clinical outcome
   Weight gain, morbidity, mortality
8. Cessation of feeds
9. Economic outcome (cost of formula, cost of equipment)

Results

Patient profile

Sixty-nine patients with cerebral palsy (CP) had a gastrostomy placed during the nine year study period (Table 1). Forty-four patients (64%) had the gastrostomy tube placed via the percutaneous endoscopic gastrostomy tube method (PEG). Twenty-three patients had an open Stamm gastrostomy procedure with a fundoplication performed under the same anaesthetic. The joint open procedure was performed in patients with evidence of pathological GOR prior to gastrostomy tube placement. Only 2 patients had an open surgical gastrostomy alone.

The age at insertion of gastrostomy tube was an average of 5.8 years (range 5 months to 20 years) (Table 1). Patients who received a surgical gastrostomy were slightly younger than PEG patients (5.2 years versus 6.7 years).

Table 1: Patient details

	PEG procedures	Surgical open gastrostomy procedures	Combined PEG and open procedures
Patient numbers	44	25	69
Patient age at gastrostomy insertion	6.7 years	5.2 years	5.8 years
Fundoplication			
Pre- gastrostomy	2	-	2
With gastrostomy	1	23	24
Post- gastrostomy	13	-	13

Enteral Feeding Regimen

Almost half of the patients (n=30) had a period of naso-gastric tube feeding prior to the decision to place a gastrostomy tube or while waiting for this procedure to be performed. The duration of the period of naso-gastric tube feeding varied between 1 month and 5.2 years with a mean of 10.6 months.

Nutritional requirement was calculated for each individual patient based on age, sex, medical condition, nutritional status and nutritional goals. The mean estimated energy requirement was 1094 kcal/day (± 260 kcal/day). No significant oral intake was documented in 40 patients (60%) receiving HEN. Thirty-four % of patients attempted some oral intake but in only 4 patients was this considered nutritional significant to rely on the gastrostomy tube feeds as supplementary to oral intake. This result is reinforced by the data documenting the proportion of estimated energy requirement that was provided via the gastrostomy tube. Feeding via the gastrostomy tube was successful in achieving estimated energy

requirements in the patients in this study. The mean energy provided by HEN was 89% (± 16%) of estimated requirements. Over two-thirds of patients received 90% or greater of their energy requirement by the gastrostomy tube.

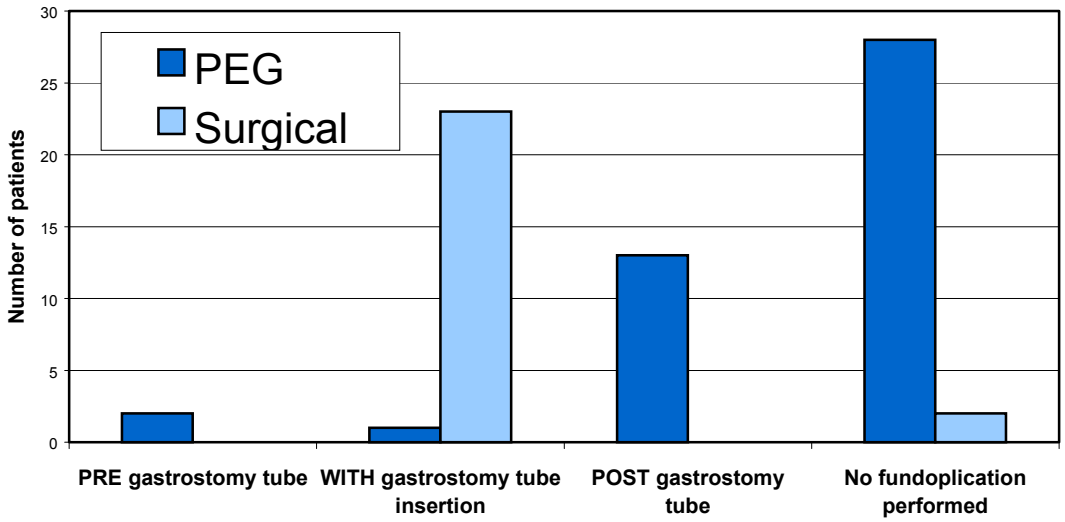
The majority of patients (63%) received formula with an energy concentration of 1 kcal/ml. Twenty-three patients (30%) required fortified feeds of greater or equal to 1.3 kcal/ml to meet estimated energy requirements.

The most common method used for the administration of the enteral feeds was by gravity feeding (67%). Overnight continuous pump feeds were uncommon in this patient cohort with only 16% patients fed by this method.

Clinical Outcomes

Forty-six patients (two-thirds) were followed for a minimum of 1 year and 37 patients (55%) were followed for greater or equal to 2 years following gastrostomy tube insertion. Weight gain was observed in all patients following gastrostomy tube insertion. Weight gain tended to be maximal in the first year following gastrostomy tune placement, with a mean of 5 kg (± 3.3 kg) gained in the first year and a mean of 7 kg (± 4.1 kg) gained over the first 2 years following gastrostomy tube insertion. Two patients gained weight until 12 to 18 months post-tube placement but lost weight again by 2 years. One patient had an acute weight loss immediately following gastrostomy tube insertion (17.5 kg to 15.1 kg at 3 months) but regained weight by 18 months and at 2 years weighed 20 kg representing a total weight gain of 2.5 kg.

Figure 1: Fundoplication in patients with feeding gastrostomies



Linear growth was inconsistently recorded in this retrospective study. This is likely due to the well recognised difficulties in accurately measuring height in CP patients who may have limb deformities, quadriplegia and/or scoliosis.

Gastrostomy tube placement was associated with the development or worsening of GOR in some patients. Thirteen patients (30%) required a fundoplication following gastrostomy tube placement for the treatment of pathological GOR that failed to respond to medical management. The importance of pathological GOR in this patient population is underscored by the high rate of fundoplication procedures in 39 of 69 patients (56%) required either; pre-, post- or associated with the gastrostomy tube insertion (Table 1, Figure 1). The evaluation of patients for the presence of clinically significant GOR prior to placement of the initial gastrostomy tube clearly influenced the type of gastrostomy tube placed in most patients. Patients with prior evidence of GOR had a combined open surgical gastrostomy/fundoplication procedure. However, despite recognising the potential risk of GOR in this patient group 30% of patients having a PEG procedure needed to go back to theatre for a fundoplication at a later date due to

worsening GOR. Once commenced on HEN via gastrostomy tube, no patient survivors ceased HEN therapy.

During the 8-year period of the study, 19 patients (28%) died. The mean duration between gastrostomy tube insertion and death was 19.5 months (range 2 to 40 months). No deaths were directly attributed to the gastrostomy tube. In 5 patients death was related to respiratory complications including pneumonia and respiratory failure. It is not known how many of these patients had underlying scoliosis or restrictive lung disease. Ten of the 19 patients who died had had a fundoplication procedure. But of the 5 patients whose death was attributed to respiratory disease only one patient had had a fundoplication.

Economic outcomes

The cost of providing the formula and equipment to these patients was a mean of $144 per month. Seventy-five % of this cost was due to the cost of the formula (mean $107.70 $\pm$ $72.62). However, there was significant patient variability of costs particularly for equipment where the standard deviation was $44 per month compared with a mean cost of $36.67 per month. This may reflect the cost of replacement of different types of gastrostomy tubes and connections or the different method of delivery (i.e. continuous pump versus gravity or bolus feeding). No infrastructure costs or costs of patient review were able to be accurately determined for this retrospective study.

Conclusions

1. Gastrostomy tube placement is a common and valuable method of providing nutrition to infants and children with CP
2. Energy goals can be successfully obtained in patients with minimal, if any, oral intake using HEN therapy delivered via a gastrostomy tube
3. Weight gain is identified in all patients following insertion of the gastrostomy tube, however occasional patients may have difficulty maintaining weight gain
4. GOR is common in patients with CP.
5. The identification of pathological GOR is influential in the clinical decision of the most appropriate method of gastrostomy tube insertion.
6. Unlike in adult practice where most gastrostomy tubes are placed using the PEG technique, in paediatric practice, a significant number (36%) of gastrostomy tubes are placed using the open surgical technique usually associated with a fundoplication procedure.
7. Thirty percent of patients require a fundoplication after gastrostomy tube placement due to pathological reflux which did not respond to medical treatment.
8. The mortality of CP patients receiving HEN was 28%. The gastrostomy tube insertion or the provision of gastrostomy tube feeds did not directly attribute to death in any of these patients. Five patients died due to a respiratory cause, although the relationship to feeds or possible reflux could not be established.
9. The cost of providing HEN was approximately $144 per month although there was significant patient variability particularly in the cost of equipment.

HOME ENTERAL NUTRITION IN CHILDREN WITH CEREBRAL PALSY - A prospective review

Investigators:

R.G. Heine, V. Dalton, R. Bourke, A.G. Catto-Smith, M.R. Oliver, D.S. Reddihough & J.E. Bines

Background

In October 1997 the HEN Service was introduced at the Royal Children's Hospital. This service aims to improve management and follow-up of patients receiving long-term enteral nutrition. The HEN team is multi-disciplinary and has a strong emphasis on parent/caregiver and staff education.

Increased GOR is common after gastrostomy placement and may lead to growth failure or potentially life-threatening aspiration. This has been observed after both surgical (STAMM) and percutaneous endoscopic gastrostomy (PEG). If medical therapy fails to control the GOR, then a surgical antireflux procedure may be necessary in up to 30% of patients [1]. This considerably increases both morbidity and costs related to the enteral feeding program for that patient.

Causes for this increased GOR are not clear, but it may be related to an exacerbation of pre-existing disturbed gastro-oesophageal motor activity and delayed gastric emptying. Limited data from an earlier study certainly suggested that delayed gastric emptying is a strong risk factor for the failure of a stand-alone gastrostomy (without anti-reflux procedure) for HEN.

The present study aimed:

(1) To prospectively review of use of percutaneous endoscopic gastrostomy versus surgical gastrostomy and fundoplication in children with CP
(2) To assess if nutritional short-term rehabilitation is achieved
(3) To assess if best practice guidelines are followed
(4) To survey patient and parent/caregiver satisfaction with HEN service

Methods

All patients undergoing gastrostomy placement between November 1998 and February 2000 were recruited into the prospective study. Oesophageal 24-hour pH monitoring and nuclear medicine gastric emptying studies and were performed before gastrostomy placement, as deemed necessary by the treating clinician. If the gastrostomy was placed endoscopically, biopsies were taken from the oesophagus, stomach and duodenum. Patients were weighed at the time of gastrostomy placement and about 3 monthly thereafter during out-patient visits. Standard deviation scores (Z scores) for weight-for-ages were calculated using the epidemiological software package Epi Info, Version 6.04 .

Results

Twenty-five patients with severe CP underwent gastrostomy placement in the 15 months' study period. The mean age at gastrostomy placement was 6.8 years (SD ± 5.75; median 3.9; range 0.7 to 22.1). Four (16%) patients had their gastrostomy placed surgically, 3 of whom also underwent fundoplication. The remaining 21 (84%) patients underwent a percutaneous endoscopic gastrostomy (PEG) procedure.

The need for an antireflux operation determined whether a gastrostomy was placed endoscopically or surgically. In one patient with a large hiatus hernia and severe scoliosis a PEG was attempted but could not be safely performed due to the anatomical abnormalities in this patient. This patient later had the gastrostomy placed laparoscopically without a concurrent fundoplication.

Oesophageal 24-hour pH monitoring

Sixteen patients underwent oesophageal 24-hour pH monitoring as part of their pre-gastrostomy investigations for GOR. Of these, 5 (31%) were abnormal with a fraction reflux time (FRT) > 5%. The details of oesophageal

The 24-hour pH monitoring are summarised in Table 1.

Table 1: Oesophageal 24-hour pH monitoring

	Mean	SD	Median	Minimum	Maximum
Number of reflux episodes	38	30.93	36.5	1	100
Duration longest episode [min]	3.3	4.22	1.5	0	13
Duration time with pH < 4.0 [min]	51.0	46.20	53.5	1	178
Fractional reflux time with pH < 4 [%]	3.74	3.30	3.8	0.1	13.0

Oesophageal histology

Of 20 patients who had oesophageal biopsies collected at the time of endoscopic gastrostomy placement, 14 (70%) had histologic evidence of oesophagitis. This was graded as mild in 8, moderate in 3 and severe in 3 patients. Of the patients with oesophagitis, 8 had undergone oesophageal pH monitoring, 5 of whom had a (false-negative) normal result.

Nuclear medicine gastric emptying scintigraphy

Gastric emptying studies were performed before gastrostomy placements in 16 patients. Of these, 4 (25%) showed delayed gastric emptying. This was defined as a gastric emptying half-time of > than 50 minutes or a residual gastric volume at 2 hours post ingestion of the radionuclide of > 15%. The details of the gastric emptying studies are summarised in Table 2.

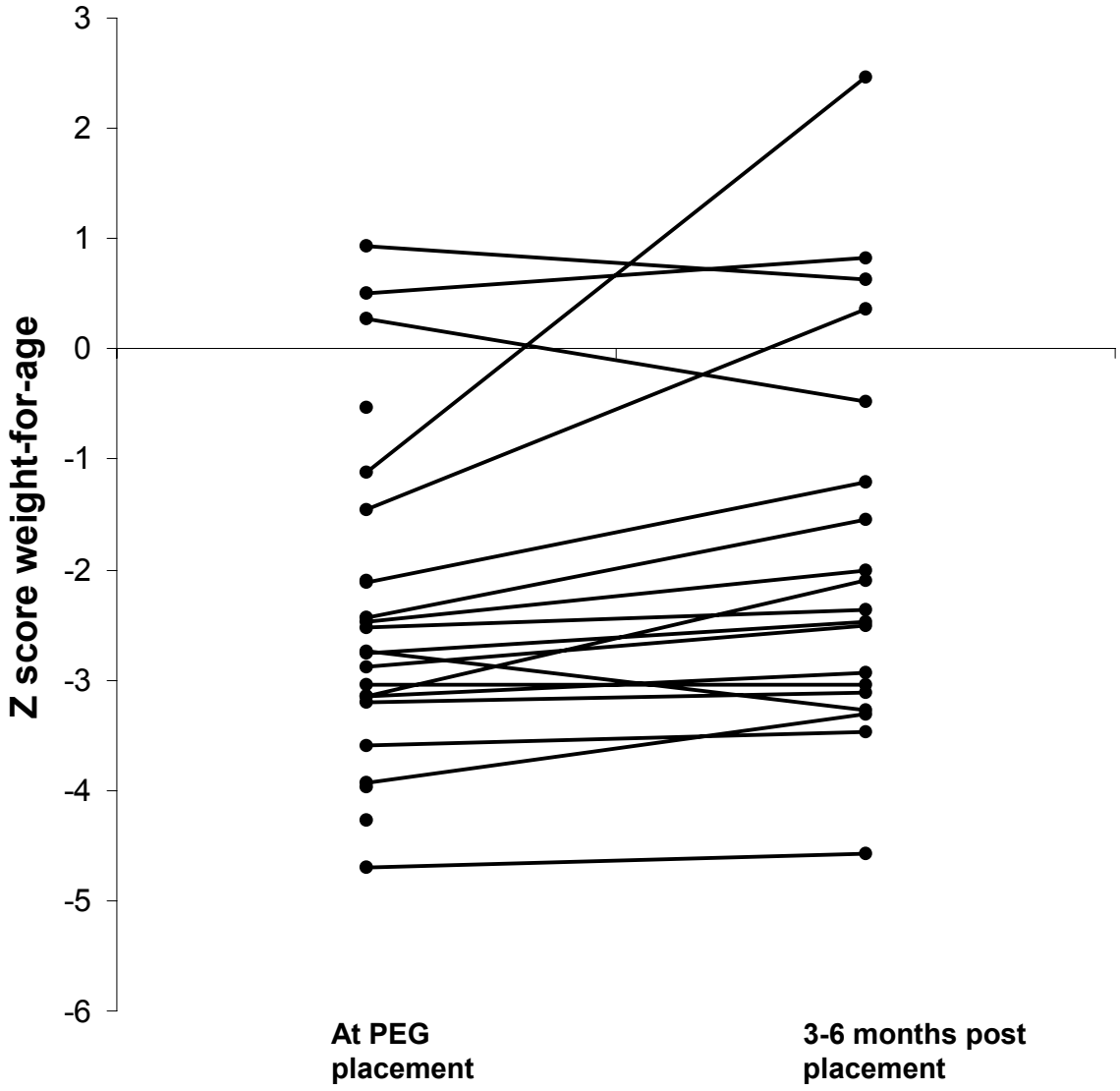
Table 2: Gastric emptying studies

	Mean	SD	Median	Minimum	Maximum
Emptying half-time [min] (normal < 50 minutes)	37.0	27.58	22.5	16	96
Residual volume at 2 hours [%] - (normal < 15%)	11.38	15.12	4.5	1	42

Weight gain

As a group, patients were significantly malnourished at the time of PEG placement (mean Z score for weight-for-age –2.36 ±1.52; range –4.7 to 0.93). Follow-up data was available for 19 patients. There was a significant improvement in Z scores follow-up 3-6 months after the initial procedure (-1.79 ± 1.80; range –4.57 to 2.46, t test p=0.03).

Figure 2: Z-scores for weight-for-age at PEG placement and follow-up



CONCLUSIONS

1. Gastrostomy placement was tolerated well in all 25 patients without significant procedure-related morbidity.

2. As a group there was a significant increase in weight-for-age Z scores suggesting successful short-term nutritional rehabilitation in the majority of patients.

3. 20% of patients had evidence of pathological GOR on 24-hour oesophageal pH monitoring. This was in contrast to endoscopic and histological findings where oesophagitis was present in 70% of patients. This result is in agreement with findings from our previous study on gastrostomy placement in children with CP [1] we found poor agreement between oesophageal pH monitoring and biopsy findings.

4. Routine oesophageal biopsies at the time of PEG placement should be taken to determine the whether oesophagitis is present.

5. Four of the 16 patients undergoing nuclear medicine gastric emptying studies had evidence of delayed gastric emptying. This did not always correlate with increase GOR or feeding intolerance. The usefulness of this investigation in the context of the high cost needs further evaluation.

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CYSTIC FIBROSIS

Home Enteral Nutrition in Cystic Fibrosis: An overview

Cystic fibrosis (CF) is an inherited disease that affects many organ systems including the lungs, pancreas and the liver. The lung disease is the main determining factor of both length and quality of life of many of these patients. Treatment of the lung disease is an important factor in the long-term survival of these patients, however nutrition is another significant factor in increasing the average age of survival of these patients.

Patients with cystic fibrosis (CF) often cannot meet their excessive energy requirements caused by poor absorption from the gut and by chronic chest infection. Some patients with CF receive overnight supplemental gastrostomy feeds. In the past this has been used only in severely affected patients and has had the stigma of palliative care. The impact of an early nutritional intervention on the progression of disease and quality of life on the course of disease needs to be further defined. The three studies in this proposal on patients with CF will be done in close collaboration with The Alfred Hospital. This will significantly strengthen the bond between the two main Victorian CF Services and facilitate the smooth transition of care for adolescents and young adults with CF.

In the past many clinicians have attempted to break this cycle of progressive weight loss and deteriorating lung function by providing short-term nutritional support (1). Unfortunately, none of these studies have demonstrated long lasting improvements in either lung function or body composition. However long term nutritional rehabilitation has been shown to improve body composition, weight gain and in many cases stabilise the function (2). Some studies have even shown improved lung function, at least in the short term, probably by improving lung mechanics due to increased strength of the chest muscles.

The current guideline that is set down for consideration of gastrostomy placement is a weight for height of less than 85% of the predicted value (3). There are studies that have suggested that even patients with severe lung

dysfunction with an FEV1 of 25% can benefit so long as they fit the above-mentioned criteria, with improved body mass index and stabilisation of lung function over a twelve month period (4). Whilst others have suggested that there is no benefit to the patient unless their FEV1 was greater than 40% (5). The results from our retrospective study would support the latter and would hence suggest that baseline lung function is an important predictor of outcome and should be considered prior to placement of gastrostomy. In our retrospective study we also demonstrated that poor adherence in relation to gastrostomy tube usage was associated with a lower weight-for-age Z (WAZ) score both before and after placement of gastrostomy which suggested that these patients were probably generally non-adherent with their treatment. This will be studied further in the prospective study and is probably a crucial factor in the future success of gastrostomy feeding in this patient population. The prospective study also focuses on the quality of life issues brought about by gastrostomy placement with such only being superficially dealt with by the published literature. The preliminary results will be presented later.

Finally, can the intervention of gastrostomy feeding cause any harm to the patient in terms of lung function? Many patients who have had a gastrostomy placed report difficulties with vomiting, especially during severe coughing spells. We also know that GOR is a common problem in patients with CF and can correlate with severity of lung function (6). In our retrospective study patients who reported vomiting and or oesophagitis had a greater fall in the weight for age Z score and lung function when compared to children who did not report GOR. It has been postulated that this increase GOR may be due to the fixation of the stomach to the anterior abdominal wall by the gastrostomy and that this may result in reduced lower oesophageal sphincter pressure. It is also possible that the placement of a gastrostomy may alter the volume and compliance of the stomach, which may lead to delayed gastric emptying and can result in GOR. An increase in GOR may result in poor clearance of gastric contents from the proximal oesophagus resulting in aspiration into the lungs. Which in the CF population could lead to rapidly deteriorating lung disease. Our retrospective data would support this hypothesis, but this is best assessed by a prospective study

(which is currently in progress). This study is unique in that there are no other published works that examine this important issue in the CF population, which would have an obvious impact on clinical care.

A RETROSPECTIVE AUDIT ON THE USE OF HOME ENTERAL NUTRITION IN VICTORIAN CHILDREN WITH CYSTIC FIBROSIS

Investigators:

MR Oliver, RG Heine, H Ng, E Volders, JR Thompson, A Olinsky

Aims

The aims of our study were to (a) assess the effects of long-term gastrostomy feeding on nutritional state and lung function in children with CF, (b) examine factors that may adversely affect an improvement in these parameters and (c) report adverse events that occurred as a result of gastrostomy placement and use.

Methods

We identified 36 patients attending our CF clinic between 1989-1997 who had required gastrostomy placement for supplemental feeding. All patients had the diagnosis of CF confirmed on the basis of clinical manifestations and a positive sweat test. Gastrostomy placement had been recommended on the basis of the CF Nutrition Consensus Committee's definition of nutritional failure and only after intensive dietary counselling concerning the use of oral supplements over a 3 month period had failed. During this time the patient was closely monitored by our multi-disciplinary clinic, which included a thoracic physician, gastroenterologist, dietician and clinical psychologist and are provided with written and graphic information regarding gastrostomy and enteral feeds. All patients were pancreatic insufficient on the basis of a 3 day faecal fat balance or qualitative evidence of fat malabsorption in conjunction with a clinical history of steatorrhoea. Patients with severe carbon dioxide retention were excluded from the study because of the risk of this problem worsening with intensive supplemental feeding.

Weight, height and respiratory function were measured on at least a 3 monthly basis. Z-scores for weight and height were calculated using standard software

and spirometry measurements were standardised using a percentage predicted forced expiratory volume in 1 second (FEV1), for height, weight and gender. Measurements of adherence to therapy (gastrostomy feeds) were made on the basis of self-reported use of the tube. All patients were asked to use their gastrostomy tube for supplement feeding 5 to 6 nights per week, so that patients were reported as being non-adherent if they did not use the tube at all or infrequently (less than twice weekly). This was recorded every 3 months and patients were only placed in the non-adherent group if they reported poor use of the gastrostomy on at least 2 of 4 outpatient visits over a one-year period. Data concerning gastro-oesophageal reflux (GOR) were available both at the time of gastrostomy placement and during the first 6 months following gastrostomy placement. Patients were asked at outpatient visits if they had regular vomiting or regurgitation (daily), infrequent symptoms (1-2 per week) or no symptoms at all. Patients who reported severe GOR prior to surgery had a combined gastrostomy and fundoplication and those who reported GOR after tube placement were treated with either or a combination of a prokinetic agent, H_2 receptor antagonist or a proton pump inhibitor.

Other data that was recorded included genotype, oesophageal biopsy results (at gastrostomy placement and at the time of change from the initial tube to a low profile device) and complications related to the gastrostomy. The number of hospitalisations and length of inpatient stay pre and post gastrostomy feeds were also compared. After placement patients were prescribed supplements providing 30-40 kcal/kg per day by continuous drip overnight. Commercially available formulas were used, with 10 patients requiring elemental feeds. All patients on non-hydrolysed feeds required pancreatic enzyme supplements that were administered prior to the initiation of the overnight feeds.

Data Analysis

Data was presented as mean ± standard deviation. Averaged data for time periods were used for making comparisons between patients. For this purpose the study was divided into 4 time periods, that is 2 years before, 1 year before, 1 year after and 2 years after gastrostomy placement. Data on each patient was also compared between consecutive time periods, so that a relative change in a measured variable was possible. These variables were then compared using a paired or unpaired two-tailed *t*-test. Linear regression analysis was performed on the FEV1 data.

Results

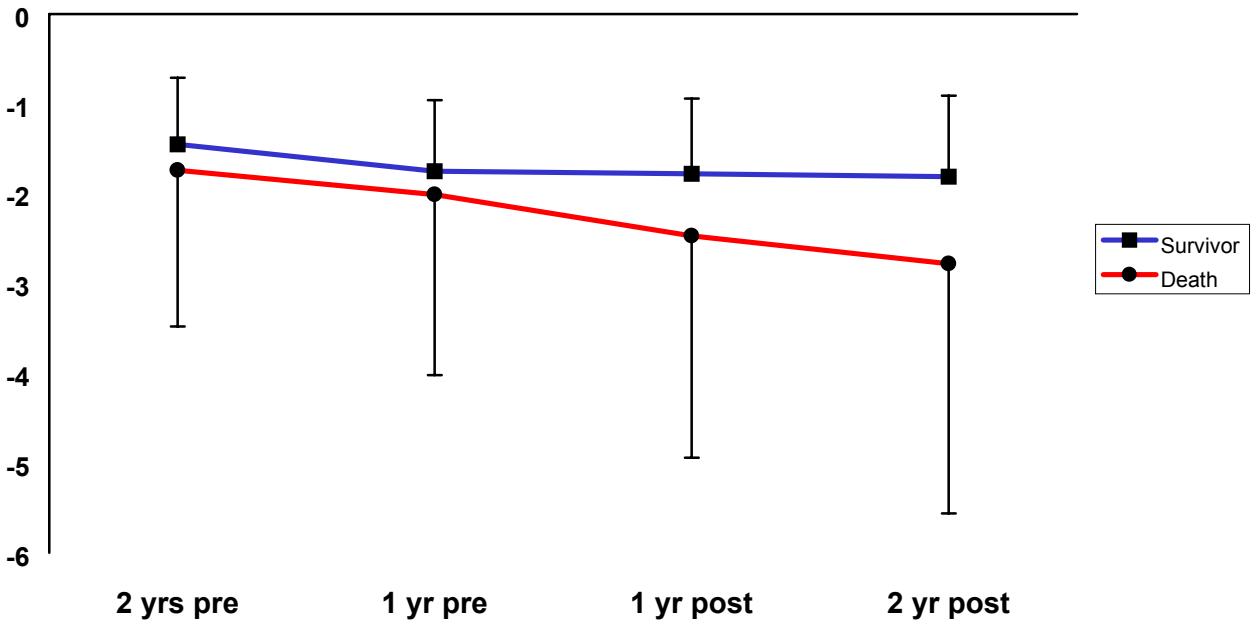
Of the 36 patients that were reported in this study (16 female and 20 male), 11 patients died during the two year follow-up. Of these patients, 8 were female and 3 male. There was no difference in the mean age of patients at time of gastrostomy placement between those who died when compared to those who survived the study period of 4 years (survivors, 11.7 ± 4.93 years *vs* 11.3 ± 4.77 years in non-survivors). The number of in-patient admissions and length of stay were not significantly affected by placement of gastrostomy and supplemental feeding in our patients. Delta 508 homozygosity was present in 50% of the survivors and 54% of the non-survivors.

Weight for age (WAZ) data

In the survivors (n=25) the averaged WAZ scores were –1.75 ± 0.79 during the year prior to gastrostomy placement compared to non-survivors (n=11) who had a WAZ score of –2.00 ± 0.53 (p=0.34). However, after gastrostomy placement as can be seen in figure 1, there was a significant reduction in the WAZ scores in the non-survivor group. This change was most marked in the first 12 months after gastrostomy placement (survivors, WAZ-0.03 ± 0.34 *vs* non-survivors, -0.47 ± 0.47; p=0.003) and was greater in the female population during this same time period (-0.3±0.41 *vs* 0.07± 0.42; p=0.05).

FIGURE 1:

Z scores for weight-for-age for survivors and non-survivors (*n* = 36)



Forced expiratory volume 1 (FEV1) data

In the survivors, the averaged percent of predicted FEV1 in the year prior to gastrostomy placement was 57.25±14 compared to non-survivors who had a mean FEV1 of 47.8±11.5; p= 0.03). As can be seen from figure 2 this difference became more pronounced in the year after gastrostomy placement. Again this decline was greater in the females when compared to the males (-10.6 ± 7.6 *vs* –5.0 ± 11.28; p=0.067). The average decline in FEV1of the entire cohort was 5.3% (SD 9.3) in the year after gastrostomy placement.

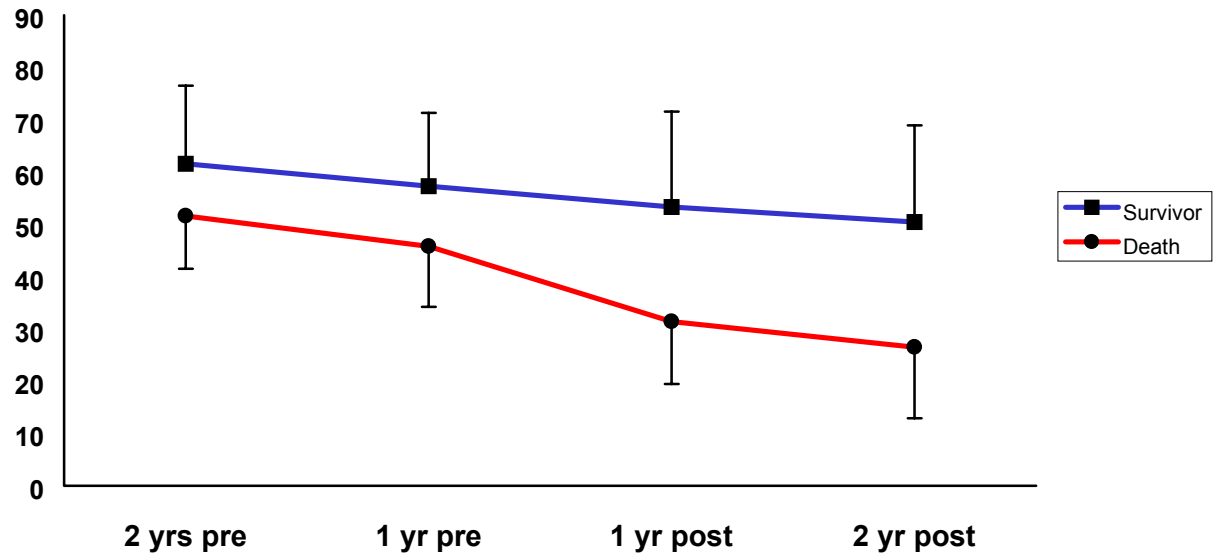
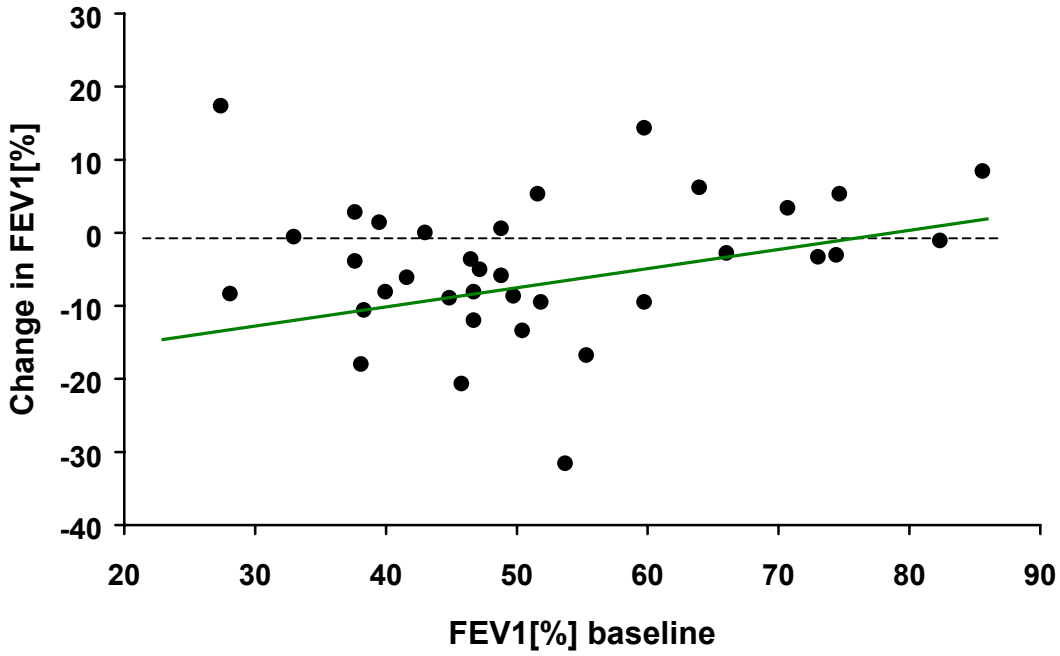


FIGURE 2:

FEV1 [%] predicted for survivors and non-survivors, (n=36).

On regression analysis this fall in FEV1 was less marked in children who had a higher pre-surgical FEV1 (p=0.04). This data is summarised in Figure 3.

FIGURE 3: Base-versus-gain analysis of FEV1% at the time of gastrostomy



Height for age (HAZ) data

This is summarised in table 1 and as can be seen there was no statistically significant difference between survivors and non-survivors at the different time periods, but there is an obvious trend that the fall in HAZ score was greater in the non-survivors after gastrostomy placement.

Table 1: Height for age Z score data (non-survivors vs survivors)

HAZ			
Study time	Non-survivors	Survivors	p value
2 yrs pre-gastrostomy	-1.1 ± 1	-1.3 ± 1.6	0.75
1 yr pre-gastrostomy	-1.3 ± 0.9	-1.47 ± 1.6	0.74
1 yr post-gastrostomy	-1.54 ± 0.85	-1.43 ± 1.1	0.76
2 yrs post-gastrostomy	-2.01 ± 0.6	-1.46 ± 1.17	0.36

Gastro-oesophageal reflux (GOR)

Data regarding GOR was available for 34 patients, with 11 reporting regular vomiting and or regurgitation after gastrostomy placement and 23 not reporting any consistent symptoms. In 21 patients, oesophageal biopsies had been obtained with 13 having evidence of mild to moderate histological oesophagitis and 9 having normal biopsies. To assess the effect of GOR and oesophagitis on WAZ and FEV1 we compared this data from the year before and after gastrostomy placement. As can be seen in Table 2, patients who had symptomatic GOR had a greater reduction in the WAZ than those who did not report GOR (-0.32 ± 0.26 *vs* 0.03 ± 0.39; p=0.03). This also appeared to be the case for the FEV1 data but was less marked (-11.9 ± 6.4 *vs* –4.9 ± 11; p=0.07)

Table 2: Gastro-oesophageal and oesophagitis data

	% predicted FEV1	p value	WAZ	p value
with GOR (n=11)	-11.9 ± 6.4	0.07	-0.32 ± 0.26	0.03
without GOR (n=23)	-4.9 ± 11		-0.03 ± 0.39	
with oesophagitis (n=13)	-11.6 ± 9	0.12	-0.19 ± 0.35	0.11
without oesophagitis (n=9)	-5 ± 7.58		0.02 ± 0.24	

Adherence to treatment

Data was available on 31 patients, with 22 being classified as being regular users of their gastrostomy and 9 being non-adherent. The effects of adherence to gastrostomy feeds on WAZ scores are shown in figure 4. As can be seen there were moderate differences at all time periods in the WAZ scores in the adherent *vs* non-adherent patient groups. With patients who reported good adherence with treatment having a higher WAZ score than the non-adherent group.

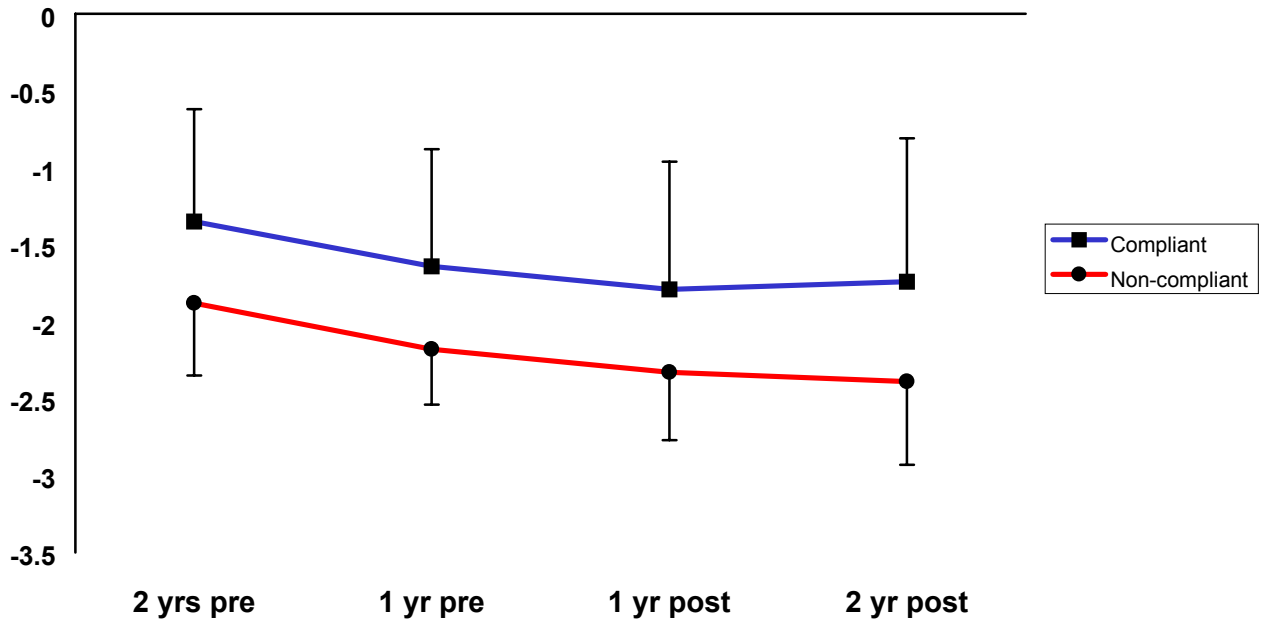


FIGURE 4:

Z scores for weight-for-age in compliant and non-compliant patients

Other complications related to the gastrostomy

Gastrostomy feeding was generally well tolerated, with 30% of patients reporting mild stomal leakage and 17% having cellulitis, which required antibiotic treatment. Two patients developed diabetes mellitus within 6 months of starting gastrostomy feeds and none had overt symptoms of aspiration of feeds into the lungs.

Costs

Costs for feeds, gastrostomy equipment (for administration of enteral feeds) and increased costs for pancreatic enzymes amounted to approximately $4,900 per patient for year. This did not take into account a significant amount of time invested in these patients by both medical and allied medical staff.

EFFECTS OF GASTROSTOMY PLACEMENT ON GASTRO-OESOPHAGEAL REFLUX (GOR) AND ITS RESPIRATORY CONSEQUENCES IN CHILDREN WITH CYSTIC FIBROSIS

Investigators

MR Oliver, AG Catto-Smith, A Olinsky, RG Heine

Aims

To assess the effects of gastrostomy placement on gastric and oesophageal motor function and GOR (as measured by 24hr pH probe monitoring of the lower oesophagus). We also assessed the effects of gastrostomy placement on respiratory function and aspiration of gastric contents into the lungs.

Methods

Patients with CF who fulfilled the current criteria for gastrostomy placement were invited to participate in this study. Patients were excluded from the study if they had severe end stage lung disease or oesophageal varices related to liver disease. All proposed investigations would be performed prior to and during placement of the PEG and would be repeated 8 weeks later when the initial PEG is routinely changed to one that is aesthetically more appropriate for long term use. Investigations include (a) oesophageal pH monitoring, (b) oesophageal manometry, (c) gastric emptying, (d) oesophageal biopsy, (e) spirometry, (f) non-bronchoscopic bronchoalveolar lavage and symptom score chart.

Results

This study required to be passed by the Human Ethics Committee of our hospital. As a result of the delay, only one patient was recruited into the study. Others have refused permission. One issue has been the invasive nature of oesophageal manometry, which we have now excluded from the study. In the future this will allow greater numbers of patients to be recruited into the study.

The patient who was studied has his results summarised in Table 3.

Table 3: Gastro-oesophageal reflux data

Patient 1	Before gastrostomy	After gastrostomy
oesophageal manometry	normal study	Not completed
24 hr oesophageal pH monitoring	0.8% for 6 hrs only	Not completed
gastric emptying	normal	normal
oesophageal biopsy	oesophagitis	normal
GOR questionnaire	mild reflux symptoms	increased reflux symptoms

PROSPECTIVE EVALUATION OF HEN IN MALNOURISHED PATIENTS WITH CYSTIC FIBROSIS

Investigators:

MR Oliver, RG Heine, A Olinsky, E Volders

Aims:

The aims of this study, which is ongoing, is to assess the effects of HEN on
(a) pulmonary function and growth
(b) quality of life issues, and to assess effects of adherence to treatment on lung function and weight gain.

Methods:

Patients with CF were prospectively recruited into this study. The main inclusion criteria were the same as outlined for the retrospective study, however, we actively excluded other conditions that were potentially reversible and may adversely affect outcome. Growth data including weight, height and skin fold thickness, as well as pulmonary function, were collected. Biochemical assays of vitamins, liver function, albumin, haemoglobin and HbA1C were also assessed pre and post gastrostomy placement. Adherence to usage of gastrostomy was checked by assessing number of times prescriptions were filled with our Pharmacy for feeds or on self-reporting. A validated quality-of-life questionnaire was also administered both before and after gastrostomy placement. In addition to this, a data base concerning gastrostomy tube complications and expenses were established, as this information was not readily accessible with the retrospective study. An assessment of patients/parents' perceptions of the value of information provided to them during the admission about the procedure and further management of the gastrostomy was also assessed. We collected 3-monthly measurements of pulmonary function, anthropometry and growth data. The remainder of the baseline information was collected at 6 and 12 months after gastrostomy placement.

Results

To date baseline data has been collected for eight patients (4 female and 4 male, age range 4-20 years). Two patients died within nine months of having their gastrostomy. The lung function data are summarised in Tables 4 and 5. No statistical analysis of this data was possible as a result of low patient numbers. Preliminary review of the quality of life questionnaire is summarised in table 6. In summary, the majority of patients found the preparation, education materials provided and teaching by ward staff to be adequate. Most families agreed that the gastrostomy had positive effects on their child's self esteem and they also felt better. However, this initial group of patients felt that the gastrostomy had not reduced the number of chest infections and there were considerable concerns about vomiting, tube dysfunction and body image.

Table 4: Lung function in prospectively analysed patients

FEV1 (% Predicted)			
Patient	Baseline	6 months	12 months
1	56.5	67.1	41.2
2✝	26	✝	✝
3	38	38	41
4✝	38	34	20.9
5	55.6	48	—
6	34.8	36.7	—
7	65.2	—	—
8	40.6	—	—
✝ = deceased, — = ongoing data collection			

Table 5: Height and weight for age Z scores

Heights, weights and Z-scores												
Patient	Baseline				6 months				12 months			
	Wt	**Z**	**Ht**	**Z**	**Wt**	**Z**	**Ht**	**Z**	**Wt**	**Z**	**Ht**	**Z**
1	32.25	-2.55	150.6	-1.74	39.6	-1.92	154	-1.68	39.35	-1.19	159.4	-1.5
2✞	34	-2.38	151	-1.59	✞	✞	✞	✞	✞	✞	✞	✞
3	38	-1.11	153	-0.62	43.25	-0.83	154.8	-0.82	43.6	-1.03	156	-0.96
4✞	47.5	-1.26	165	+0.22	50.8	-0.81	165	+0.22	47.1	-1.31	165	+0.22
5	50	-2.1	173	-0.58	56.2	-1.41	174	-0.42	—	—	—	—
6	28.25	-1.24	138.5	-0.67	26.55	-1.76	141.4	-0.63	—	—	—	—
7	39.7	-0.94	157	-0.14	—	—	—	—	—	—	—	—
8	17.4	-0.87	110.7	-0.71	—	—	—	—	—	—	—	—
✞ = deceased, — = ongoing data collection												

Table 6: Quality of life data

Quality of life questionnaire				
Question number	Topic	Strongly agree or agree	Not sure	Disagree or strongly disagree
1	Preparation	5	1	0
2	Education	4	2	0
3	Education	5	1	0
4	Time	1	2	3
5	Time	2	2	2
6	Health	3	2	1
7	Self esteem	4	1	1
8	Health	1	4	1
9	Activity	1	1	4
10	Time	3	2	1

CONCLUSIONS

The outcome of success of an intervention can be measured in several ways. In the retrospective study we focused on results that could be easily obtained by such a study design. Patients were divided into two groups: those that survived and those that died within 2 years after gastrostomy placement.

Our findings were as follows:

1. Death after gastrostomy placement in children with CF was associated with a failure to achieve weight gain within 12 months after gastrostomy placement. This decline was most marked in the female population.

2. A low weight for age Z score (WAZ) that is less than –1.75 or a low FEV1 (less than 45% of predicted) at the time of gastrostomy placement was also associated with poor outcome.

3. Mortality was highest in females in whom the mortality rate was 67% versus 28.5% in males.

4. Poor compliance with reference to using gastrostomy feeds was associated significantly with poor WAZ scores.

5. There was no survival or response differences (WAZ and FEV1) based on genotype.

6. Patients who reported GOR after gastrostomy placement had a significant reduction in WAZ and FEV1 in the year after the tube was placed.

The study assessing the effects of gastrostomy on “GOR and its respiratory consequences” is ongoing. This study will need to be modified so as to make it more acceptable to the patient and though we cannot at present come to any firm conclusions it will be important to complete.

The prospective study focuses on quality of life, patient satisfaction and costs is ongoing. The preliminary results are interesting in that it suggests that though the effects of gastrostomy tube feeding is generally seen as beneficial, there are still many issue that need to be addressed. These include patient concerns of gastrostomy care and complications, that gastrostomy may have an adverse effect on physical activity and the cosmetic effects of gastrostomy (especially in females).

FUTURE RESEARCH

1. Assessing interventions aimed at improving patient adherence to treatment and it's effect on outcome.

2. Parenteral nutrition as an intervention in patients failing to gain weight within a 3-6 month period after gastrostomy placement despite the usual clinical manipulations.

3. Assessing the effects of early intervention on outcome in a prospective manner.

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FEEDING AVERSION

PARENT-CHILD INTERACTIONAL FACTORS INFLUENCING SUCCESS WITH ORAL FEEDING PROGRAMS FOR INFANTS RECEIVING ENTERAL NUTRITION

Investigators:
L Ferguson & C Paul

Introduction

This component of the Home Enteral Nutrition Program (HENP) sought to evaluate the experience of prolonged enteral tube feeding for the pre-verbal child (aged 0-3) and their parents. Considerable anecdotal experience from the Royal Children's Hospital, other clinical experience and studies reported in the literature (Spalding and McKeever (1998), Douglas and Byron (1996), Geertsma *et al*. (1995)) suggest that it often is difficult for the child to proceed to normal oral feeding after a prolonged period of tube feeding. Oral feeding can become aversive and the child resistant to resuming ordinary eating activity. Many children and families find it hard to commence eating a full range of food types textures and tastes. When eating by mouth resumed there has frequently been described a very narrow and restrictive range of foods or food textures taken. For example, a five year old child who would drink only milk from a babies bottle or a six year old child who would eat only one particular brand of smooth canned baby food. Other children have been unable to resume oral feeding although medically able to do so.

Behaviourally based programs have been reported in the literature (Blackman (1985), Linsheid *et al.* (1987), Lamm *et al.* (1988), Foy *et al.* (1997), Handen (1986), Dunbar *et al.* (1991)). Most of these programs involve inpatient stays and the length of time taken to reach full oral feeds varies form one month to more than 24 months. Little attempt has been made to explain variations in the success of programs. Clinical experience suggests that numerous factors combine to influence the success of feeding programs. Bazyk (1990) studied medical and other factors, which predict outcomes of intensive feeding programs.

Parent-child interaction is known to be an important factor in a child's food refusal (Lindberg 1996, Budd *et al.* 1992). Chamberlin (1990), described a group outpatient program which, while primarily relying on positive reinforcement and consequences for non eating, also took account of the feelings of families involved. The introduction of a long term feeding tube has various meanings for the child and for the child's family (Thorne *et al.* 1997. Radford *et al*. 1997). Chattoor *et al*. (1992) discussed the conceptualisation of the feeding tube as "trauma" and consequent food refusal as a post traumatic symptom. Disruption of the parent-child interaction might be attributed to the presence of the feeding tube.

Methods

Children between the ages of 0-3 years who have had a gastrostomy tube or a nasogastric tube in place for long-term feeding were recruited from medical and surgical units at the Royal Children's Hospital.

Inclusion criteria included:

- the need for the child to be medically stable enough to begin some level of oral nutrition;
- that tube feeding will be the main form of nutrition for at least six months and
- that the child and family will have not participated in an intervention program aimed at increasing oral intake before the commencement of the study.

The subjects in the study received developmentally based speech pathology treatment program which aimed at increasing their tolerance of oral experiences and they also received parent-child psychotherapy which was aimed at helping the infant and parents accommodate to the experience of tube feeding and subsequent attempts at oral feeding. Assessments were repeated at six months after the first intervention. The feeding and child psychiatric interventions were video taped and subject to a feeding interaction checklist and qualitative analysis.

Data Collection

- Videotapes of mealtime, prior to and following the treatment period were rated using the Feeding Interaction Checklist (Macphee &Schneider, 1996). (Ratings incomplete).
- Feeding checklist, questionnaire (Appendix 1) was completed by phoning parents following the treatment period (see Table 1).
- Data regarding parental reaction to their child's feeding problem and the feeding tube were extracted from videotaped interviews and from clinical notes taken during initial sessions.

Nature of Interventions

For each child the intervention comprised two main components. The speech pathology intervention offered detailed analysis of the child's previous and current feeding experiences in conjunction with the child's parent. The speech pathologist offered practical advice regarding feeding techniques, useful equipment and suitable food and drink appropriate to the child's medical, physiological and developmental stage. Suggestions were made to modify the time, place and personnel involved in meal times and encouraged the fostering of appropriate independent meal time behaviour. Force-feeding was discouraged and alternative strategies for encouraging the child to drink or eat were presented and often modelled by the therapist in intervention session. New tastes, smells and foods were offered during sessions.

All subjects received a minimum of 6 sessions of speech pathology intervention (range 6-14). For all but one of the subjects these sessions were conducted at the Royal Children's Hospital, mainly as an outpatient but also during inpatient stays. One subject lived interstate and received further speech pathology intervention through a community agency. Speech pathology sessions at RCH took place within the hospital setting. The child seen by the community agency was visited at home by the speech pathologist. When appropriate, joint speech pathology/child psychiatry sessions were held. Sessions were usually one hour in length and were scheduled to coincide with medical reviews at the hospital.

Speech pathology intervention type varied according to the needs of the child and the family.

Attempts were made to help the parents integrate the physiological experience of eating with the social, emotional and inter-actional experience of the feeding situation. This was discussed overtly and also modelled by the therapist and infant.

The mental health intervention attempted to address both the general developmental and emotional experiences of the infant and family and to explore the specific emotional significance of the tube feeding for the infant and parent. During the psychotherapeutic sessions with parents and the infant, issues relating to the child's primary problem, for example, oesophageal atresia, were discussed allowing parents to ventilate their anxieties, frustration, despair and concerns about the primary problem and the child's general outlook. The mental health intervention provided an opportunity for parents to discuss their anger and ambivalence, their fears and concerns about their child and those caring for her. Parents were able to discuss their initial responses to the placement of the tube feeding, their attitude to feeding their own child through a tube and how decisions between the parental couple were made as to who would undertake the feeding process.

It was notable that there was significant overlap in roles between the speech pathologist and child psychiatrist. Parents appeared able to talk readily to both clinicians about their approach to the practicalities of feeding as well as their emotional experience of the tube feeding.

Results

Recruitment of sufficient numbers of children, who met all the inclusion criteria, proved to be very difficult. Similarly it was very difficult to recruit control children who had been tube fed for six months or more and had not received some speech pathology or psychological input. Additionally, the group of children who did meet the selection criteria proved to be a very heterogeneous group who had a wide range of medical and surgical reasons for their inability to take oral nutrition.

Table 1: Subject data

	Age (months)	Diagnosis	Feed type	SP/MHS sessions	I.P.days ##
Subject 1	5	Oesophageal Atresia	Gastrostomy	8	131
Subject 2	7	Severe Failure to thrive	Naso-gastric *	10	228
Subject 3	4	Oesophageal Atresia	Gastrostomy	14	195
Subject 4	3	Oesophageal Atresia	Gastrostomy	9	100
Subject 5	6 **	Bronchopulmonary Dysplasia***	Naso-gastric	6	230
Subject 6	11	Pierre Robin Sequence***	Naso-gastric	6	123

* gastrostomy tube inserted later.

** 3 months corrected for prematurity

*** tracheostomy tube

2 further cases withdrew

length of Inpatient stays, in days.

As a result of this project the researchers saw 15 further children and their families. These children did not meet the criteria for inclusion in this study because of the severity of their neurological disorder, provision of parenteral nutrition concurrent to their enteral nutrition or inability to participate in the study for other reasons. Families of these children faced similar issues to those reported for the research subjects.

Themes from the mental health interview

Since the current sample size is small, quantitative analysis of the parent's experience has not yet been undertaken, however, certain common themes have emerged. The commencement of tube feeding was generally a medically necessary decision, for an urgent or severe surgical or nutritional problem. Although parents were not responsible for making this decision alone, most approached it with reluctance and anxiety. Some parents expressed concern about how their infant would experience the intrusion of the tube into their body and were concerned about how they would manage. They generally saw it as an artificial device which was necessary in order for their child to grow and develop. Some parents feared that the tube would become an almost permanent component of their child's experience.

Consistent with the experience reported by Spalding and McKeever (1998) there seemed to be an initial feeling of relief and resignation as the tube was inserted. Parents reported that their child seemed to gradually became accepting of the tube and two parents reported that the child seemed to find some sense of security from being able to hold and touch the tube at times.

In common with other parents of children with chronic illness, the parents of the children who were tube fed tended to see the problems facing their child as too complex for "ordinary doctors" and they relied very much on the small group of specialists. At times however, they were relieved to be able to talk to someone who was outside the immediate clinical team. It seemed safe to discuss their frustration, anger and confusion in this context without feeling that it might interfere with their child's optimal care.

At times parents presented a feeling of despair that the problem facing their child may never end and that somehow they may have been to blame for the problem in the first place. Self blame and a feeling that they had to present as if they were always coping well, were also phenomena described. At times parents felt

that they had lost control of the care of their own infant and that this was taken over by the medical and nursing staff.

The intervention sessions provided an opportunity to talk about this ambivalence towards the hospital. Some parents reported recurrent fears and intense anxiety. They seemed to have an emotional re-experiencing of particular traumatic episodes relating to their child's primary problem. Their anger and frustration they feared was sometimes directed towards their child as well, although they knew that the child was not deliberately making life difficult.

Although at times ambivalent, both parents and children were accepting of the tube, as they were its eventual removal.

Outcomes

All but one child in the experimental group were established on a full oral diet. One child continued enteral feeds but achieved some oral intake (Table 2).

Table 2: Food Accepted Orally

Pre-treatment

FOOD ACCEPTED ORALLY				
	liquid	puree	mash	Solid
Subject 1	1	1	0	0
Subject 2	1	1	0	0
Subject 3	1	0	0	0
Subject 4	1	0	0	0
Subject 5	1	1	0	0
Subject 6	1	2	0	0

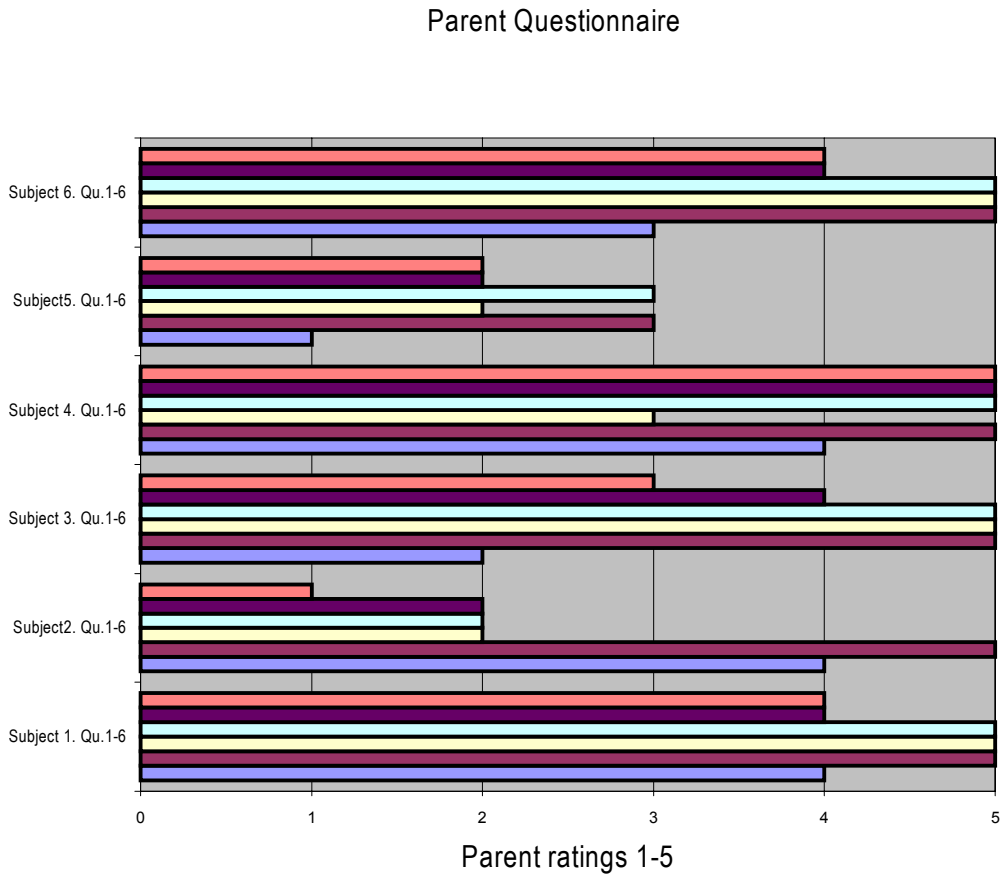
Post-treatment

	FOOD ACCEPTED ORALLY			
	liquid	puree	mash	solid
Subject 1	3	3	3	3
Subject 2	1	1	0	0
Subject 3	3	3	0	0
Subject 4	3	3	3	3
Subject 5	3	3	3	3
Subject 6	3	3	3	3

0=nil
1=some
2=most
3=all

Parents of all six subjects completed a phone questionnaire (Appendix 1) regarding attitudes to their child's tube feeding. This questionnaire was given following the intervention phase. Responses were in the form of a rating score of between 1 and 5 for six questions. Responses are summarised in Table 3.

Parents provided a rating score of between 1 and 5 in response a series of 6 questions (see Feeding Checklist, Appendix 1)



Response to mental health intervention

The small sample size makes firm conclusions about the parents and infant's response to the mental health intervention difficult. There was one family who did not wish to proceed with the formal project study after they were enrolled, however they have maintained contact with the speech pathologist and child psychiatrist and are willing to participate in further interviews. The other families readily participating in the project did not appear to be distressed by the intervention. A more systematic follow up survey regarding the family's evaluation of the intervention is planned.

Conclusion

Given the limitation of the small sample size and the very mixed nature of the problems, with which the infants presented, these conclusions are presented with caution. It seemed that the provision of a safe and non-stigmatising environment in which parent and infant were able to explore feeding and feeding behaviour in the context of prolonged tube feeding was beneficial. The children in the study demonstrated an improvement in developmentally appropriate feeding behaviour and in five of the six cases the tube feeding were able to be ceased. The intervention by both speech pathologist and child psychiatrist was accepted and well utilised by parents and infants. Parents valued the non-stigmatising and non-conditional availability of the opportunity to discuss in detail their infant's feeding problem, the primary medical problem and their own feelings about it. They also seemed to value the opportunity to talk about their experiences of the Hospital and of other medical and nursing practitioners and also the response of their own extended family. Analysis and modelling of optimal feeding behaviour was well tolerated by both infant and parent.

Future Plans

A more detailed and quantitative analysis of the pre and post videotapes of feeding and mental health interview shall be undertaken as an extension of this project. This data will be submitted for journal publication when completed.

There should be further follow up of the eventual feeding nutritional and growth outcome of the children in the study.

Treatment modalities other than those used in the study (eg. group treatments) should be considered and evaluated.

The data base established for this study should be extended to include data for those not meeting the strict criteria for the current study.

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Appendix 1.

PARENT QUESTIONNAIRE.

Question 1. <u>How well did you accept the feeding tube?</u>

Not at all	1	2	3	4	5	Accepted the tube very well.

Question 2. <u>Was the tube useful?</u>

Not at all	1	2	3	4	5	Extremely useful.

Question 3. <u>How well did your child tolerate the feeding tube?</u>

Not at all	1	2	3	4	5	Tolerated tube very well.

Question 4. <u>What does your child think of food?</u>

Hates it	1	2	3	4	5	Loves it.

Question 5. <u>How wide is the range of different foods accepted by your child ?</u>

No food	1	2	3	4	5	Normal family food.

Question 6. <u>How wide is the range of textures accepted by your child?</u>

Liquid only	1	2	3	4	5	Full range of textures.

EVALUATION OF EDUCATIONAL MATERIALS

EFFECT OF SPECIFIC EDUCATIONAL SUPPORT ON USE OF MEDICAL RESOURCES IN RELATION TO GASTROSTOMY FEEDING

Investigators:
AG Catto-Smith, MR Oliver, R Bourke, S Dohle, J Wells

Background

As HEN therapy becomes a more common and available mode of nutritional therapy there are increased demands on the families, caregivers and the community to provide support and care for patients requiring this therapy. Whilst hospital staff are well trained in the management of enteral nutrition administration and gastrostomy tube care, many general practitioners, community centres and regional hospitals may be unfamiliar with tube management. Although there is a long history of safe and effective administration of enteral nutrition in the home in Victoria, inappropriate feeding regimens, tube and stomal care can be associated with significant patient morbidity. Incorrect gastrostomy tube replacement has been directly related with patient death.

Many community general practitioners feel inexperienced and lack confidence in gastrostomy tube management. This is not unreasonable in view of the recent increase in gastrostomy tube use and the rapidly changing types of gastrostomy and feeding techniques. As a result, patients and their families and caregivers make extensive use of hospital Emergency Departments for gastrostomy related problems. This is a frustrating exercise for these patients and contributes to significant patient dissatisfaction observed with HEN patients prior to the initiatives brought about through the HEN program by the Department of Human Services.

The HEN Best Practice Guidelines by the Australian Society for Parenteral and Enteral Nutrition emphasises the importance of a multidisciplinary approach to HEN provision. While dietitians have been traditionally associated with enteral nutrition therapy, this document recognises the importance of the doctor, stomal therapist and/or nurse practitioner in the care of the patient receiving HEN via a gastrostomy tube. The ultimate goal of HEN therapy is to focus on the patients therapy and care in the home and local community. Ideally the involvement of the community general practitioner or regional physician or surgeon would provide a convenient and appropriate local focus for ongoing HEN treatment and gastrostomy tube care. To achieve this goal it is desirable to improve the education and support in HEN treatment and gastrostomy tube care aimed at patients and their families, and community and regional general practitioners.

Aim

The aim of this study is to develop education and resource material in hard copy and as an Internet-based program in HEN treatment and gastrostomy tube care for patients, their families and caregivers, and community general practitioners.

Methods

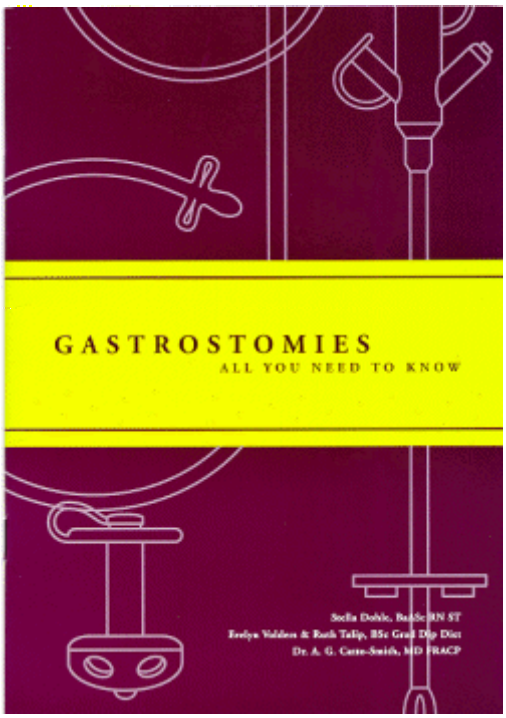
The aspects of the education program included:

1. Development of patient Information Booklet: “Gastrostomies : all you need to know”
   S Dohle, R Bourke, E Volders and AG Catto-Smith
2. Development of “A practical guide to Paediatric Nutrition Support”
   J Bines, D Jessen, M Humphrey, T Titchen
3. An Internet-based HEN program

Development of patient Information Booklet:
"Gastrostomies : all you need to know"

S Dohle, R Bourke, E Volders and AG Catto-Smith

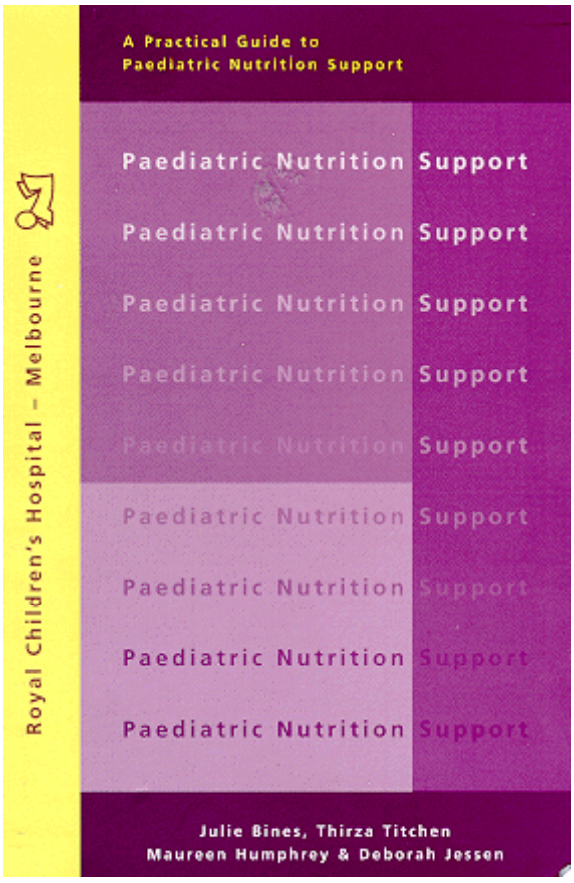
This booklet introduces the basis of gastrostomy tube feeding, the main types of gastrostomy tubes and the recognition and management of complications. This booklet was first published in 1997 with the financial assistance of this grant. The booklet has been very well accepted with over 1000 copies being distributed throughout Australia to patients or centres with patients with gastrostomy tubes. This print run is now completely sold out. The patient response to this educational booklet was assessed by questionnaire and the results are shown in the report presented previously. The booklet has now been reviewed containing the changes recommended from the patient review as well as containing updated information. A draft of the changes for the new edition is enclosed in the appendix. This booklet is given to all patients prior to gastrostomy tube placement at the Royal Children's Hospital and is sold through the Child Health Information Centre to many other hospitals and health care professionals around Australia.



Development of "A practical guide to Paediatric Nutrition Support"

J Bines, D Jessen, M Humphrey, T Titchen

This is a small text that outlines a practical approach to determining the most appropriate route and formula composition for children requiring nutrition support. This text includes nutritional assessment, details of formulas and complications associated with enteral nutrition therapy. It is aimed at general practitioners and regional paediatricians who care for patients requiring nutrition support.



Internet-based HEN program

An Internet page focussing on HEN therapy is in the final process of development. This page will be accessed through the Women's and Children's Network Website. This website already contains the patient booklet for HEN therapy and details for ordering hard copies of this or the Nutrition Support Guide through the Child Health Information Centre.

The HEN Internet Program is a web-based educational program which will provide a pictorial description of common and less common problems encountered with gastrostomy tubes and during HEN therapy. We have scanned over 150 images of tube related complications. Where appropriate therapeutic algorithms will be provided. Due to the increasing numbers of general practitioners connected to the Internet we anticipate that this will be an important resource and educational program. Once this program has been launched the formal evaluation of effectiveness of the program will be completed in patients and general practitioners in the Bendigo area.

Conclusion

A highly successful patient education booklet has been developed receiving good acceptance locally and nationally. The first edition has been fully sold and a second edition has been developed taking into consideration feedback from a patient assessment questionnaire. A Paediatric Nutrition Support handbook has been developed to provide general practitioners and regional paediatricians with education on nutrition assessment, formulas and complications of tube feeding. The patient booklet is accessible through the Women's and Children's Network Website.

The Internet-based HEN education program is being developed with a pictorial description of complications of gastrostomy tubes. This is expected to be accessed through the Women's and Children's Healthcare network by June 2000.