Percutaneous endoscopic gastrostomy in cystic fibrosis : patient acceptance and effect of overnight tube feeding on nutritional status

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Abstract

Background : **Malnutrition remains a common problem in cystic fibrosis (CF) patients, despite pancreatic enzymes and hypercaloric diet advice. When oral supplementation fails, additional overnight gastrostomy tube-feeding is a therapeutic option.**

Methods : **In our centre gastrostomy tube feeding is proposed when weight for height drops below 85% despite intensive dietetic counselling. All the CF patients at our centre (n = 11) receiving gastrostomy tube feeding were evaluated for changes in nutritional status and pulmonary function. Complications of percutaneous endoscopic gastrostomy were inventarised and patients older than 7 years and all the parents were asked to fill in a questionnaire concerning subjective well-being with gastrostomy supplemental feeding.**

Results : **The patients received 40% of the recommended daily allowances (RDA) for energy by tube feeding. Total daily energy intake increased by 30%. Within 3 months this resulted in a significant improvement in nutritional status expressed as percentage of ideal weight for height or body mass index z-score. After 6 months a significant catch-up growth was detectable. Pulmonary function remained stable. The complications were local irritation (n = 4), night sweating (n = 1) and bed-wetting (n = 1). The gastrostomy was well accepted.**

Conclusion : **Gastrostomy appears to be a good and safe way to improve nutritional status, growth and mood of the CF child. As decreased pulmonary function plays a crucial role in the growth of the CF child, full normalisation of growth pattern is not achieved despite catch-up. Gastrostomy tube feeding should perhaps be used earlier to optimalise growth.** (Acta gastroenterol. belg., **2004**, 67, **241-244**).

Key words : nutritional status, growth, cystic fibrosis, gastrostomy tube feeding.

Abbreviations

CF	Cystic Fibrosis
BMI	Body mass index
W/H%	percentage weight for height of p50
RDA	Recommended daily allowances
FEV1	forced expiratory volume in 1 second
FVC	forced vital capacity
GSTF	Gastrostomy tube feeding
s.d.	Standard Deviation
PEG	Percutaneous endoscopic gastrostomy

Introduction

Although the cystic fibrosis (CF) consensus committee on nutrition stated several years ago that there was no reason to accept malnutrition or impaired growth in CF, it still remains a serious and frequent problem (1,2,3). Malnutrition dramatically impairs the prognosis in CF (4,5). However, the best way to tackle this problem at different stages of the disease is still a matter of debate since there persists a need for randomised controlled studies (6,7). The nutritional status correlates well with daily fat intake (8). CF centres use dietary advise, oral supplements, behavioural therapy, tube feeding and parenteral nutrition to maintain a good nutritional status in their CF patients. All methods improving caloric intake result in a better nutritional status.

Since randomised studies are unethical when dealing with malnutrition, descriptive reports from different CF centres on the effect of different methods are useful. The effects on the nutritional status and respiratory function of overnight gastrostomy tube feeding in CF children are reported. Moreover the patients' personal appreciation of this type of intervention is evaluated.

Patients and methods

The data of all the CF patients receiving overnight gastrostomy tube feeding (GSTF) were retrospectively analysed. The patients received a percutaneous endoscopic gastrostomy (PEG) (type Freka PEG, Ch 15) placed with general anesthesia which was replaced by a button gastrostomy (type Freka Button) after 6 weeks. This procedure was also performed with general anesthesia and the internal plate of the PEG tube was endoscopically removed.

Data on weight, height, pulmonary function and caloric intake from 2 years before and after the gastrostomy insertion were collected. Body mass index (BMI) z-scores, height z-scores and percentage weight for height of the P50 (W/H%) according to Gerver (9) were calculated. The pulmonary function was measured on a "Jaeger Masterscreen Body". The food intake is calculated as % of the recommended daily allowances (RDA) for normal children as recommended by the National Research Council (10).

Patients from the age of 7 were submitted asked to fill in a questionnaire concerning acceptance and problems with their gastrostomy. Parents were asked to comment on the way the gastrostomy had been was presented and the manner on how they were prepared on complications

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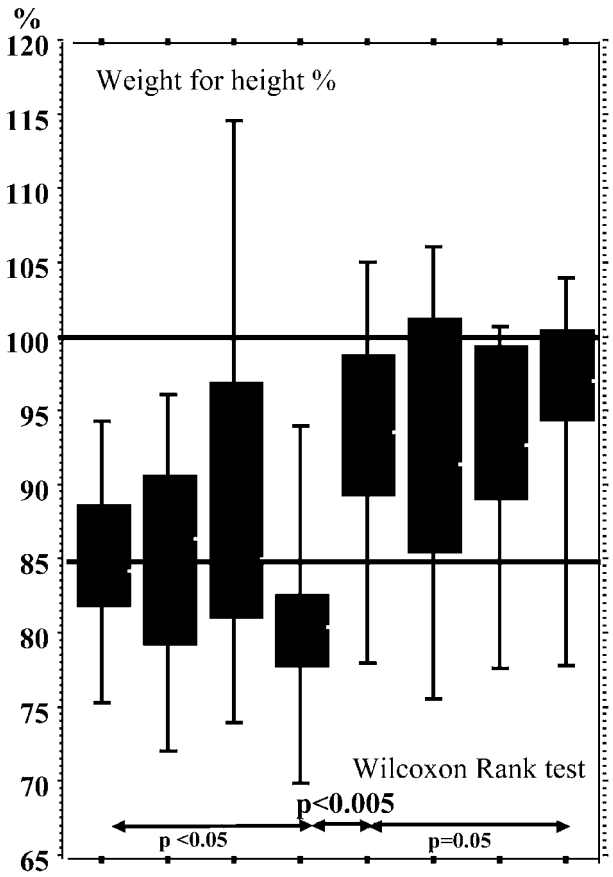

Fig. 1. — Box plot of the evolution of the weight for height percentage of the p50 of a normal population of the total study group during the 2 years preceding and following the gastrostomy placement. In every box plot the number of patients for which the data were available is indicated. Significant changes are indicated by arrows accompanied by the p-value. A significant improvement of the nutritional status is seen within 3 months.

and handling of the gastrostomy. A non-validated questionnaire on personal appreciation and the influences the gastrostomy tube had on their daily life.

Computer analysis of the data was performed with Statview V, using the nonparametric paired Wilcoxon rank test. Results are presented as median values. The range is shown between brackets.

Results

Patient data

In our centre 130 patients of whom 11 patients received GSTF (8 female, 3 male) are followed. A gastrostomy is advised when W/H% falls below 85% or severe stunting with a length below -2 standard deviation (s.d.) of the normal population. The median age was 9.4 year (0.6-14.8 y) at the time of the gastrostomy insertion. The indication was stunting or failure to thrive in 9 (aged 7-14.8 y) and feeding disorder in 2 babies (0.6-0.8 y). Only the 2 babies with food refusal had naso-gastric tube feeding prior to the GSTF. The median duration of follow-up is 2 year (5 m-8.5 y). One patient has also celiac disease, another developed diabetes mellitus 2 years after the start of GSTF and one patient died due to a pulmonary complication 5 months after tube insertion.

Nutritional aspect

The median W/H% at start of GSTF was 81% (67-90%). In 4 patients W/H% was above 85%, in the 2 babies with naso-gastric tube feeding and 2 children with severe stunting (Length s.d. -4,66 and -3,93). The median height z-score was -2,9 (-4,66 ; -0,37). The W/H% increased within 3 months and with a normalisation in the majority (W/H > 90% n = 7/11), and after 6 months it was 91% (75-119%) (Fig. 1). BMI z-score displays the same evolution (At start -2,34 (-2,95 ; to -1,29), after 3 m -1,11 (-2,18 ; to 1,35), after 6m -1,32 (-2,04 ; to 0,63)).

Although the nutritional status does not always normalise, a catch up growth is observed within 6 months after the start of GSTF (Fig. 2). 5/10 patients achieve a growth within the 2 s.d. of the normal population within 12 m.

The caloric intake before and after the start of the gastrostomy feeding augmented with 37% (30% ; 57%) of RDA for healthy children of the same age (absolute intake : before GSTF 940-2011 kcal/day ; after 1027-2666 kcal/day). About 40% (14% ; 90%) (500-1500 kcal/night) of RDA for caloric intake is given by gastrostomy over night. The formula used is a high energy (1.5 Kcal/ml) polymeric tube feeding (fresubin energy). It is advised to take pancreatic enzyme therapy at the start, before going to bed, during the night if waking up and at the end. When using formula with 1 Kcal/ml the volume given is bigger and leads to bed wetting.

For the 2 babies the gastrostomy was proposed as being a temporary solution, however feeding problems remain despite logopedic therapy.

Pulmonary function

During the whole study follow-up period there was no significant change in pulmonary function expressed as forced expiratory volume in 1 second (FEV1%) or forced vital capacity (FVC). The number of pulmonary infections needing hospitalisation decreased not significantly (0-3 infections before, 0-2 infections after).

Acceptance and complications

The patients and parents were all but one relieved about the gastrostomy since it took away table discussions about the quantity of food that should be taken. This was an important improvement as expressed by parents and children. It is however difficult to quantify this improvement with a non-validated questionnaire, therefore a study with validated quality of life scores is

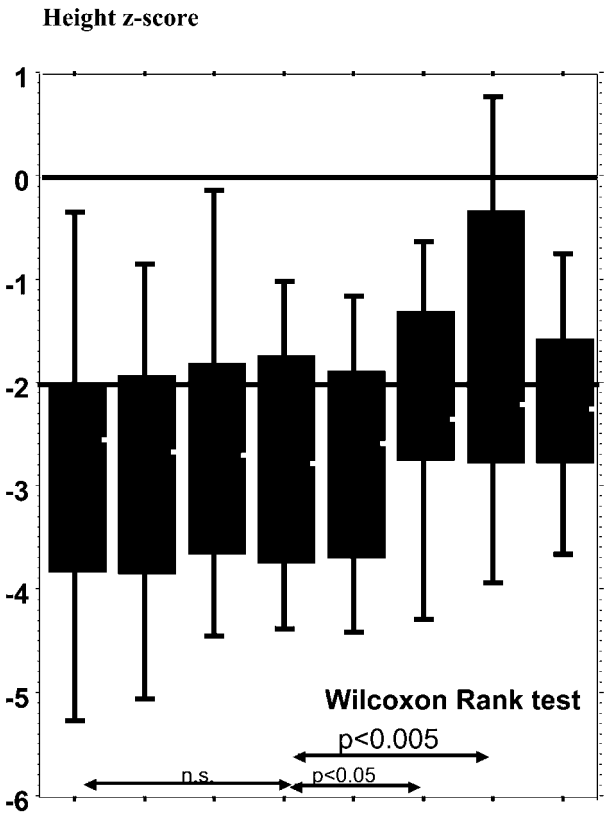

Fig. 2. — Box plot of the evolution of the height z-score of the total study group during the 2 years preceding and following the gastrostomy placement. In every box plot the number of patients for which the data were available is indicated. Significant changes are indicated by arrows accompanied by the p-value. A significant improvement of growth is seen within 6 months.

starting. The parents had more difficulties accepting the tube than the children themselves. The parents also felt that, even if they had seen the tube before on a doll, they were surprised by the disturbance of the body image of their child. Information given at that moment was easily forgotten and a clear patient manual at home is mandatory.

Many children (5/11) complain of pain when the button gastrostomy has to be changed. Local xylocain gel does not influence the pain. There were only minor complications noted : local irritation and leakage around the tube (n = 4), accompanied by local pain (n = 3). One child wetted her bed and another complained of excessive nightly sweating.

Discussion

We confirm that overnight tube feeding improves the nutritional status (11,12). The improved nutritional status can only be maintained when tube feeding is continuous continued (13). With this knowledge, a gastrostomy tube is a more comfortable and safer way than the nasogastric tube to administer overnight tube feeding (14,15,16,17).

The most important result of tube feeding in our patients was however the induction of a catch-up growth. This resulted in their positive appreciation of the gastrostomy tube. Growth pattern did, however, not normalise fully since some of the children started puberty with only a short period of growth as a consequence (3/11).

During our study-period the pulmonary function expressed as FEV1 or FVC remained stable (19,20). We did not observe a correlation between the remaining pulmonary function and the weight gain, as did Walker (21). In our patients, however, only one girl had a FEV1 below 40% of the control value.

Results of semi-elemental and polymeric nutrition are not significantly different (22). We use a polymeric hypercaloric formula (1.5 Kcal/ml). Only when there are problems taking the enzymeslipases sometimes a semi-elemental formula is used (1/11). We advise to take enzymes at the start, when going to bed, if waking up at night and before termination. There is, however, no consensus in literature about timing and dosage of the enzyme replacement therapy in CF patients receiving overnight tube feeding.

Although the diurnal oral intake of food decreased in all patients (median 10%, (1% ; 35%)), their total caloric intake improved by 37% (20% ; 57%). This resulted in a better nutritional status and a more relaxed meal-time behaviour. Disturbed meals due to tensions between parents and children regarding the quantity of food to be taken are a current problem in families with CF children (23). In the older children it is necessary to continue tube feeding to maintain the effect (19). On the long run demotivation leads to compliance problems. One of the followed patients is suspected of not using the gastrostomy. She is postpubertal and has a BMI z-score of -1,75 and a length z-score of -4,4.

Although the gastrostomy in the 2 babies was mend to be temporary it was up to now not possible to stop GSTF despite logopedic therapy. The parents are anxious to maintain a good nutritional status and stopping or decreasing GSTF seems very difficult for them.

Conclusion

Gastrostomy tube feeding is a safe, well-accepted way to improve nutritional status and growth in CF patients. Even if a catch-up growth is induced with the tube feeding, complete normalisation is difficult to obtain once the delay is so important. These results together with the results of the study of Walker *et al.* should be an argument to propose the gastrostomy earlier (21). Further studies concerning acceptance, body image and impact on quality of life of this therapy are however mandatory.

References

1. COLE T.J., FREEMAN J.V., PREECE M.A. Body mass index reference curves for the UK 1990. *Arch. Dis. Child*, 1995, **73** : 25-29.
2. MORISON S., DODGE J.A., COLE T.J., LEWIS P.A., COLES E.C., GEDDES D., RUSSELL G., LITTLEWOOD J.M., SCOTT M.T. Height and weight in cystic fibrosis : a cross sectional study. UK Cystic Fibrosis Survey Management Committee. *Arch. Dis. Child*, 1997, **77** : 497-500.
3. SINAASAPPEL M., STERN M., LITTLEWOOD J., WOLFE S., STEINKAMP G., HEIJERMAN H.G.M., ROBBERECHT E., DÖRING G. Nutrition in patients with cystic fibrosis : a European Consensus. *J. Cystic Fibrosis*, 2002, **1** : 51-75.
4. KRAEMER R., RUEDEBERG A., HARDORN B., ROSSI E. Relative untherweight in cystic fibrosis and its prognostic value. *Acta Paediatr. Scand.*, 1978, **67** : 33-37.
5. ROULET M. Protein-energy malnutrition in cystic fibrosis patients. *Acta Paediatr.*, 1994, **83** S395 : 43-48.
6. JELALIAN E., STARK L.J., REYNOLDS L., SEIFER R. Nutrition intervention for weight gain in cystic fibrosis : a meta-analysis. *J. Paediatr.*, 1998, 132-192.
7. CONWAY S.P., MORTON A., WOLFE S. Enteral tube feeding for cystic fibrosis. *Cochrane Database Syst. Rev.*, 2000 : CD 001198.
8. ANTHONY H., BINES J., PHELAN P., PAXTON S. Relation between dietary intake and nutritional status in cystic fibrosis. *Arch. Dis. Child*, 1998, 443-447.
9. GERVER W.J.M., DE BRUIN R. Paediatric morphometrics, 1st edn. Wetenschappelijke uitgeverij Bunge, Utrecht, 1993.
10. FOMON S.J., HEIRD W.C. Energy and protein needs during infancy. Academic press, Orlando, 1986.
11. AKOBENG A.K., MILLER V., THOMAS A. Percutaneous endoscopic gastrostomy feeding improves nutritional status and stabilises pulmonary function in cystic fibrosis patients. *JPGN*, 1999, **29** : 485-486.
12. WILIAMS S.G.J., ASHWORTH F., MC ALWEENIE A., POOLE S., HODSON M.E., WESTABY D. Percutaneous endoscopic gastrostomy feeding in patients with cystic fibrosis. *Gut*, 1999, **44** : 87-90.
13. DALZELL A.M., SHEPHERD R.W., DEAN B., CLEGHORN G.J., HOLT T.L., FRANCIS P.J. Nutritional rehabilitation in cystic fibrosis : a 5 year follow up study. *JPGN*, 1992, **15** : 141-145.
14. BAETEN C., HOEFNAGELS J. Feeding via nasogastric tube or percutaneous endoscopic gastrostomy. A comparison. *Scand. J. Gastroenterol.*, 1992, **194S** : 95-98.
15. MARIN O.E., GLASSMAN, SCHOEN B.T., CAPLAN D.B. Safety and efficacy of percutaneous endoscopic gastrostomy in children. *Am. J. Gastroenterol.*, 1994, **89** : 357-361.
16. BEHRENS R., LANG T., MUSCHWECK H., RICHTER T., HOFBECK M. Percutaneous endoscopic gastrostomy in children and adolescents. *JPGN*, 1997, **25** : 487-491.
17. NORTON B., HOMER-WARD M., DONNELLY M.T., LONG R.G., HOLMES G.K.T. Randomised prospective comparison of percutaneous endoscopic gastrostomy and nasogastric tube feeding after acute dysphagic stroke. *Br. Med. J.*, 1996, **312** : 13-16.
18. LEVY L., DURIE P., PENCHARZ P., COREY M. Effect of long-term nutritional rehabilitation on body composition and clinical status in malnourished children and adolescents with cystic fibrosis. *J. Pediatr*., 1985, **107** : 225-230.
19. STEINKAMP G., VON DER HARDT H. Improvement of nutritional status and lung function after long-term nocturnal gastrostomy feedings in cystic fibrosis. *J. Pediatr.*, 1994, **124** : 244-249.
20. WALKER S., GOZAL D. Pulmonary function correlates in the prediction of long-term weight gain in cystic fibrosis patients with gastrostomy tube feeding. *JPGN*, 1998, **27** : 53-56.
21. ERSKINE J.M., LINGARD C.D., SONTAG M.K., ACCURSO F.J. Enteral nutrition for patients with cystic fibrosis : comparison of a semi-elemental and a nonelemental formula. *J. Pediatr.*, 1998, **132** : 265-269.
22. STARK L.J., JELALIAN E., POWERS S.W., MULVIHILL M.M., OPIPARI L.C., BOWEN A., HARWOOD I., PASSERO M.A., LAPEY A., LIGHT M., HOVELL M.F. Parent and child mealtime behaviour in families of children with cystic fibrosis. *J. Pediatr.*, 2000, **136** : 195-200.