

*Brief report*

## **Feeding dysfunction in infants with severe chronic renal failure after long-term nasogastric tube feeding**

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**Abstract.** Nasogastric tube feeding (NGTF) is frequently necessary to overcome the inadequate caloric intake of children with severe chronic renal failure (CRF). In a multicenter retrospective study, we evaluated feeding dysfunction after tube feeding withdrawal in children with severe CRF who started long-term enteral nutrition early in childhood. We considered, almost exclusively, infants who had started NGTF very early and continued to be tube fed for at least 9 months. Twelve patients were included in the study: 8 showed significant and persistent eating difficulties, with difficulties in chewing and swallowing in 7 and food refusal in 6. For 2 patients "panic attacks" from swallowing were repeatedly reported. These problems persisted for more than year in 5 patients and between 1 and 6 months in 4. The possible feeding difficulties that may follow NTGF must be carefully evaluated. A possible means of overcoming these difficulties might include: encouraging the use of a pacifier, proposing water for spontaneous assumption, leaving the child the possibility of eating food spontaneously during the daytime, and increased support for the parents during weaning. These need prospective study.

**Key words:** Chronic renal failure – Nasogastric tube feeding – Eating difficulties

### **Introduction**

Infants with chronic renal failure (CRF) often have eating difficulties, which include reduced appetite, gastroesophageal reflux, and frequent vomiting, resulting in a low caloric intake which may contribute to growth retardation

[1, 2]. To achieve a satisfactory caloric intake, nasogastric tube feeding (NGTF) is often necessary and effective [3, 4]. However, this may lead to later eating difficulties. Few data are available and the extent of the problem may be underestimated. The aim of our study was to evaluate feeding dysfunctions following long-term NGTF withdrawal in children with severe CRF who started enteral nutrition very early in childhood.

### **Patients and methods**

Children receiving NGTF for at least 9 months and with a glomerular filtration rate less than 35 ml/min per 1.73 m<sup>2</sup> at the start of NGTF were included in this study. A questionnaire was used to obtain information following NGTF withdrawal in a retrospective multicenter collaborative study. Clinical information included NGTF duration, modalities of nutrient administration, calories provided by NGTF, and eating and behavioral difficulties following NGTF withdrawal. Forms were completed by the physicians who had treated the children.

Twelve children (6 males, 6 females) fulfilled the selection criteria and were included in the study. Their age at start of NGTF was less than 6 months in 6 patients and between 6 and 12 months in 2 (Table 1). Their renal diseases included obstructive uropathy in 5 and renal hypoplasia/dysplasia in 5 (Table 1).

### **Results**

The mean duration of NGTF was 18.4 ± 8 months (Table 1). Two feeding systems were used in the three centers: 6 patients were fed by continuous feeding (breast milk) for nearly 16 h (mainly during the night) with additional milk being offered in the remaining hours; the other 6 patients were fed continuously overnight for 8–10 h; during the daytime, they were allowed to eat spontaneously, but received milk formula through NGTF as "boluses" if they refused. NGTF provided more than 50% of the recommended dietary allowances [5] for calories for all patients, and in 6 represented the exclusive mode of nutrition for at least 5 months.

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**Table 1.** Clinical data of patients on nasogastric tube feeding (NGTF)

Patient no.	Primary renal disease	Age at start	GFR (ml/min per 1.73 m <sup>2</sup> ) at start	NGTF		After stopping NGTF	
				Duration (months)	Calories provided (average % RDA)	Eating difficulties	Duration (months)
1	Polycystic kidney disease	10 months	ESRF in PD	9	100 (for 6 months) > 50 (for 3 months)	Chewing inability Food refusal	> 2 years
2	Urinary tract malformation	4 years	10	23	100 (for 13 months)	Chewing inability Only solid food refusal	30 months
3	Urinary tract malformation	3 months	20	15	> 50 (for 10 months)	Chewing inability	5 months
4	Hypoplasia	2.3 years	7	13	> 50 (for 12 months)	–	–
5	Hypoplasia	2 years	15	15	> 50 (for 13 months)	–	–
6	Hypoplasia	5 months	17	32	100 (for 24 months)	Chewing swallowing disturbances. Food refusal	6 months
7	Urinary tract malformation	15 months	35	18	100 (for 12 months)	Chewing swallowing disturbances. Food refusal	1–2 months
8	Hypoplasia	2 months	10	23	> 50 (for 20 months)	Chewing swallowing disturbances (psychological retardation)	> 2 years
9	Cortical necrosis	8 months	6	15	100 (for 8 months)	Mild chewing swallowing disturbances	5 months
10	Urinary tract malformation	15 days	20	26	100 (for 19 months)	–	–
11	Urinary tract malformation	1 month	15	31	100 (for 23 months)	“Panic attacks” from swallowing. Food refusal	2 years
12	Urinary tract malformation	5 days	ESRF in PD	24	100 (for 24 months)	“Panic attacks” from swallowing. Food refusal	18 months

GFR, Glomerular filtration rate; RDA, recommended dietary allowance; ESRF, end-stage renal failure; PD, peritoneal dialysis

NGTF was withdrawn by progressively reducing the duration of night feeding and introducing small amounts of liquid food; after a few days, the food density was progressively increased. The amount of food given via NGTF was gradually reduced and then stopped depending on the child's reactions and behavior. Children and mothers were closely followed by dietitians and, in some cases, also supported by psychologists. On NGTF withdrawal, 4 children showed no eating problems (in only 1 patient was there a mild chewing/swallowing disturbance lasting less than 2 months). They had been on NGTF for 13–26 months and their age at the start of NGTF was 15 days, 15 months, 2 years and 2.6 years, respectively. In the other 8 children, the start of a normal alimentation pattern was difficult: the main problems were food refusal in 6 and inability to chew and swallow in 7. For 2 patients “panic attacks” from swallowing were repeatedly reported. These disorders lasted for more than 1 year in 5 patients and between 1 and 6 months in 3 (Table 1).

## Discussion

Enteral feeding has long been used to overcome poor caloric intake [2] in children with CRF [3, 4]; little is known about eating difficulties following the withdrawal of this technique [6–8]. In a retrospective multicenter study we

investigated the frequency of these disorders. We are aware that the children reported in this study have a number of peculiarities: most started NGTF in the first few months of life and the procedure was used for many months. Hence it is likely that this population does not represent the average child on NGTF in many centers. Severe eating difficulties were present in two-thirds of our patients, mostly consisting of inability to chew/swallow and food refusal. Differences between patients could be explained by differences in the age at the start and duration of NGTF and the amount of calories received.

Age at the start of NGTF appears to be important: 3 of the 4 children who were over 1 year at the start of NGTF did not show any significant disturbances, while 7 of the 8 younger children did. The duration of NGTF does not appear significant, since children with and without disturbances were fed for a comparable length of time. Similarly, the proportion of calories provided by NGTF was not different in the two groups: in fact, 2 of the patients without disturbances had received total enteral feeding for a long period.

Reports in the literature on this problem in renal patients are scarce [6, 7] and confirm the presence of important eating difficulties following NGTF withdrawal. One study offers suggestions for reducing symptoms [8]. The reasons why only some patients develop eating difficulties are unclear. Our retrospective data indicate that starting NGTF

during the 1st year of life carries a high risk of disturbances. Data from the present study and other reports suggest: (1) delay, where possible, of the start of enteral nutrition, if this does not represent a risk for the growth of the child, (2) considering NGTF as a part of total nutrition and encouraging the child to eat and drink spontaneously during the day, recording the caloric intake, and, if necessary, supplementing the caloric intake by NGTF during the night, and (4) encouraging the use of a pacifier to maintain oral tactile sensitivity. A prospective study to validate these and other recommendations is needed.

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## Literature abstracts

*Kidney Int* (1996) 50: 304–311

### Relationship between COL4A5 gene mutation and distribution of type IV collagen in male X-linked Alport syndrome

Ichiro Naito, Shinichiro Kawai, Shinsuke Nomura, Yoshikazu Sado, Gengo Osawa, and the Japanese Alport Network

The renal immunohistochemical distribution of collagen IV chains was studied with a monoclonal antibody series recognizing the  $\alpha 1(\text{IV})$  to  $\alpha 6(\text{IV})$  chains in nine males with X-linked Alport syndrome whose *COL4A5* mutation had been already identified. Two patients had a deletional mutation, six patients had a missense mutation and one patient had a splicing site mutation. The  $\alpha 3(\text{IV})$  to  $\alpha 6(\text{IV})$  chains were completely absent in the renal basement membrane of the two patients with a deletional mutation. On the contrary, in four of six patients with a missense mutation (substitution of a glycine within collagenous domain), antigenicity of the  $\alpha 3(\text{IV})$  to  $\alpha 5(\text{IV})$  chains was recognized

in the glomerular basement membrane although it was weak. In addition, one of the remaining patients showed a normal histochemical pattern of all type IV collagen chains, while the rest one showed completely absent of the  $\alpha 3(\text{IV})$  to  $\alpha 5(\text{IV})$  chains at the same pattern of deletional mutation. One patient with a splice site mutation showed complete absence of the  $\alpha 3(\text{IV})$  to  $\alpha 5(\text{IV})$  chains from the glomerular basement membrane, but weak staining of the  $\alpha 5(\text{IV})$  and  $\alpha 6(\text{IV})$  chains from the Bowman's capsular basement membrane. Our observations indicated that there is variety in the staining of the  $\alpha 3(\text{IV})$  to  $\alpha 6(\text{IV})$  antibodies among male patients with *COL4A5* mutations.

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### Disproportionate growth following long-term growth hormone treatment in short children with X-linked hypophosphataemia

Dieter Haffner, Elke Wühl, Werner F. Blum, Franz Schaefer, and Otto Mehls

Three short prepubertal children with X-linked hypophosphataemia were treated with 1 IU recombinant human growth hormone (rhGH)/kg per week sc in addition to calcitriol and phosphate supplementation over a period of 3 years. Improvement of height standard deviation score (SDS) ranged from 1.0–1.7 SD based on an increase in sitting height of 1.5–2.9 SD, whereas subischial leg length improved only

slightly by 0.3–0.9 SD. In all three patients, renal phosphate threshold concentration increased slightly and transient hyperparathyroidism was noted.

**Conclusion** Treatment of stunted children with X-linked hypophosphatemia is effective in improving growth velocity, but appears to aggravate the pre-existent disproportionate stature of such children.