ANNALS OF GASTROENTEROLOGY 2006, 19(3):270-275

Original article

Home nutrition support in pediatric patients

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SUMMARY

The aim of the study is to evaluate the feasibility and effectiveness of a Home Nutrition Support (HNS) program in a heterogeneous group of pediatric patients. Patients- methods: The medical records of 44 pediatric patients median 29(range 2m to 11,5y), enrolled in the program of Home Nutrition Support (HNS) immediately after hospital discharge, were reviewed. Data recorded during the regular follow-up (clinical profile, serial anthropometric measurements, quantitative and qualitative adaptation of the nutrition solutions during transitional periods) were assessed. Results: The clinical conditions supported were: surgical(19), non-surgical(25). HNS was delivered by oral intake(36), by nasogastric tube(5) and through gastrostomy(3). The duration of HNS ranged from 1.5-74 months (mean 26m). Three patients died from causes not related to HNS and 4 are expected to be HNS-dependent for life. Complications were documented in 30% of patients. The average weight z-score at the beginning of the HNS program was –1.4(–4.4 to 1.3). At the completion of the HNS program it was –0.5(–2.2 to 1.9). Weight and height velocity were improved in 75% and 65% of cases, respectively. There was a statistically significant difference in z-score improvement between surgical and non-surgical patients ($p<0,05$) and between patients with and without complications ($p<0.05$). There was statistically significant negative correlation between z score improvement and patient's age($p<0.05$) but no correlation with the duration of HNS. Conclusions: HNS is feasible and effective, in the management of serious chronic diseases in pediatrics. Pediatric patients can easily tolerate the oral intake of nutrition solutions. Younger patients and those with surgical problems seem to benefit the most. Patients' growth velocity during HNS is hampered by concomitant complications.

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INTRODUCTION

Disease related malnutrition may be a complication hampering the disease outcome.[1] On the other hand, growing awareness of the long-term consequences of under-nutrition in childhood have led to the integration of nutrition support in the medical treatment.[2] Compared to adults, children require a much more thorough approach in the design, initiation and monitoring of nutrition support, and attempts to achieve nutritional intake adequate for growth require frequent adjustments of the nutritional prescriptions, particularly in preschool children.[3] Thus, considering technology and care needs, nutrition support programs for children are very demanding and usually are provided during hospitalization. However, it is broadly recognized that children's emotional and cognitive functions are negatively affected under these circumstances. Emotional stress is followed by a poor outcome for both the disease and the nutritional status, prolonging, in this way, the hospitalization.[4] Furthermore children's hospitalization represents an extra burden for the rest of the family. For the above reasons Home Nutrition Support (HNS) programs are considered as a successful alternative all over the world.[4,5] The modern trends emphasize the treatment out of the hospital and within the community. On the other hand the technical developments in feeding and other necessary material, have helped to overcome a significant number of problems.[5] Therefore, if the children's clinical condition no longer requires their hospitalization, an HNS program can be followed given that an improvement in their quality of life[4] and an overall maximum rehabilitation is achieved more easily in a pleasant environment.[6] Stud-

ies have shown that pediatric patients with cystic fibrosis (CF), inflammatory bowel disease (IBD), cholestasis, liver disease and chronic renal failure (CRF) benefit from HNS.[1]

Unlike the US and other EU countries, in Greece there are no Nutrition Support teams established in Pediatric Hospitals. Furthermore, the organizations providing HNS lack standards of services and equipment required for pediatric patients. Their activities are rather limited in providing nutrition support products (solutions and relevant materials), fully reimbursed by the medical insurance company, instead of providing services. So the standards of practice in home care[7] do not apply in such cases.

The **aim** of the study was to evaluate the feasibility and effectiveness of a pilot program of HEN, coordinated by hospital physicians, in a heterogeneous group of pediatric patients.

PATIENTS - METHODS

Forty-four pediatric patients (median age 29 months, 20 boys, 24 girls), were enrolled in the pilot program of Home Nutrition Support (HNS) immediately after hospital discharge from the Pediatric Dept. of "G. Genimata" Hospital of Thessaloniki. Before hospital discharge specific instructions were given to each patient regarding the nutritional solution, the mode of delivery and the duration and intervals of regular follow- up during the HNS.

Since in this hospital there is no established nutritional care team, a pediatric gastroenterologist coordinated the program and made the initial evaluation of the health and nutritional status, as well as the decision for the need for HNS. The coordinator, assisted by a dietitian for home visits, carried out the follow- up. This included clinical examinations and laboratory tests in order to evaluate the disease progress as well as the tolerance of the feedings. Serial anthropometric measurements were made, such as weight, height, head circumference and weight – for – height. Body weight and height changes during follow-up were expressed as weight and height velocity z scores. Adaptations of the solution - quantitative and qualitative – depending on each individual's progress were made. Finally, consultations during transitional periods were of great importance in order to avoid any complications. The nutritional solutions and all necessary material, disposable or not, were reimbursed by the medical insurance company.

For the statistical analysis the MINITAB 13 statistical package was used and it included Student's t-test and linear regression analysis.

However, only 31 of the children's medical records included all the necessary information concerning the outcome of the program's application since several of the patients failed to attend all of their scheduled appointments -although they were calling regularly-. Thus, the results concerning serial anthropometry values are based on them.

The study was reviewed by the human subjects research committee, and it was determined that approval is not required.

RESULTS

The gender, age, route of nutrition and length of follow up are described in Table 1. Patients' age ranged from 2 months to 138 months (11.5 years) (median 29 months). The enteral solutions were delivered orally in most of the patients (n=35), by nasogastric tube in five children and in three through gastrostomy (Table 1). The solutions, which were used to support the nutritional status of the pediatric patients, were elemental and semi-elemental in 34 cases, polymeric in 5 children and 3 used disease-specific solutions. In addition to the polymeric or the disease specific solution, 16 patients received vitamin/mineral supplements. The total duration of the HNS ranged from 1.5 - 74 months (median 26 months). The tolerance of the oral solutions was exceptionally good. The use of alternative routes of feeding was limited to the cases that oral intake was compromised by the disease itself.

Patients suffered from many different disorders but were categorized into 2 main groups according to their primary diagnosis. The clinical conditions of patients enrolled in the HNS program were categorized as followed: a) surgical and b) non-surgical (Table 2).

Upon completion of the project, three patients (7%)

Table 1. Population Characteristics at Entry Into the Enteral Feeding Program

Male/ Female	20 / 24
Age (months): median (range)	29m (2m-138m)
Age group(%): under 12 months/ between 1-11 years	21(49)/ 22 (51)
Route of feeding: orally/ nasogastric/ gastrostomy	36 / 5 / 3
Months of follow-up: median (range)	26m (1.5m-74m)

had died from causes related to their disease and four are expected to be HEN-depended for life (9%), such as those who are suffering from a metabolic disease. Thirty-four children (79%) successfully completed the HNS program meaning by this that their clinical condition was improved and their nutritional status needed no more support. Only two patients (5%) continued the nutritional support program until they showed the anticipated health improvement.

Most of the patients improved their nutritional status, since an improvement in weight z scores for 21 out of the 31 children (75%) was observed. The average weight z score at the beginning of the HNS program was –1.4 (range –4.4 and 1.3) while the average weight z score at the completion of the HNS program was –0.58 (range –2.2 and 1.9). However, for the height z scores we were able to use only 23 children's records and we concluded that 15 patients, showed the expected improvement (65%). The average height z score at the beginning of the HNS program was –0.91 (range –5.5 and 1.8) while the average height z score at the completion of the HNS program was -0.05 (range –4.9 and 1.9). Some patients showed a reduction in their weight or height z scores, because these children had already improved these indexes to a maximum due to the parenteral nutrition received while in hospital and therefore, it was extremely difficult to further improve them. Complications related to the HNS program were documented in 30% of the cases (12% gastroenterological, 9% metabolic, 6% allergic and 3% mechanical). Most of them were not important but occurred to the patients with the most severe diseases. However, it is important to emphasize that 70% of the pediatric patients followed the nutritional support program without any complication. Furthermore, we examined the difference in z scores between surgical (mean z-score=1.2) and non-surgical patients (mean z-score=0.5) and found that surgical patients improved their z-scores when compared to non-surgical ones ($p<0.05$) (fig.1). The patients were also separated based on age (21 of the children were under 12 months, 22 were between 1-11 years) and the presence of disease complications. The comparison of weight scores between the two age groups showed that z- score was significantly higher ($p<0.05$) in the <1y old age group (mean z-score=1.1) compared to those of older ones (mean z-score=0.7) (fig.2). Additionally, patients with complications (mean z-score=1.3) had less improvement in their z-scores than children without complications (mean z-score= 0.4, $p<0.05$) (fig.3). There was no correlation between z-scores and the duration of the HEN program for each patient.

Table 2. Indications for HEN

Surgical (*n*)	**Non-surgical (*n*)**
Short bowel syndrome (14)	Food induced enteropathy (9)
Other gastrointestinal surgery (5)	IBD (4)
	Congenital Metabolic disorders (3)
Cholestasis (3)	Neurological disorders (3)
Cardiac disease (1)	Schwachman syndrome (1)
Pierre-Robin syndrome (1)	

Table 3. HNS related Complications

Diarrhea	4
electrolyte disturbances	2
rickets	1
milk protein allergy	2
mechanical	1

DISCUSSION

Based on the data provided by the study of this heterogeneous group of pediatric patients, it is concluded that HNS is a feasible, well-tolerated and effective component of the management of serious chronic disease in pediatrics. The pediatric patients can easily tolerate the oral intake of the nutritional solutions and the feeding through tubes or stomas is necessary only in rare cases. Patients of younger age and those with surgical

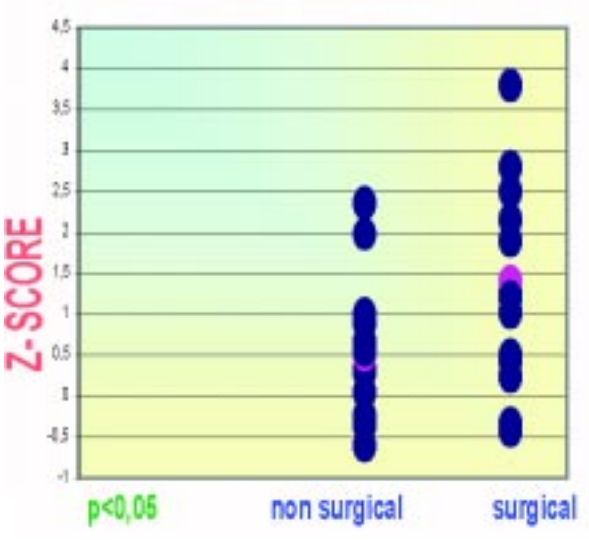

Fig. 1. Weight z-score improvement between surgical and non surgical patients ($p<.05$)

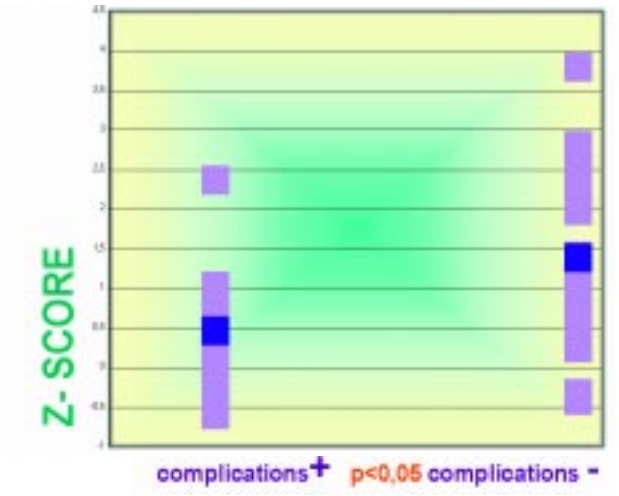

Fig. 2. Weight z-score improvement between patients with or without complications ($p<.05$)

problems seem to benefit the most. The growth velocity during HNS is hampered by concomitant complications.

Vanderhoof and Young[8] reported that enteral nutrition in pediatric Short Bowel Syndrome (SBS) is a key component in facilitating a child's growth and development. In addition, the use of enteral nutrition promotes intestinal adaptation and avoids numerous complications associated with long-term parenteral nutrition. In the present study, 7 children out of 12 with SBS showed an increase in both weight and height z-score and only one child showed no improvement. Furthermore the outcome in these cases was the most rewarding in terms nutritional status as well as clinical condition improvement.

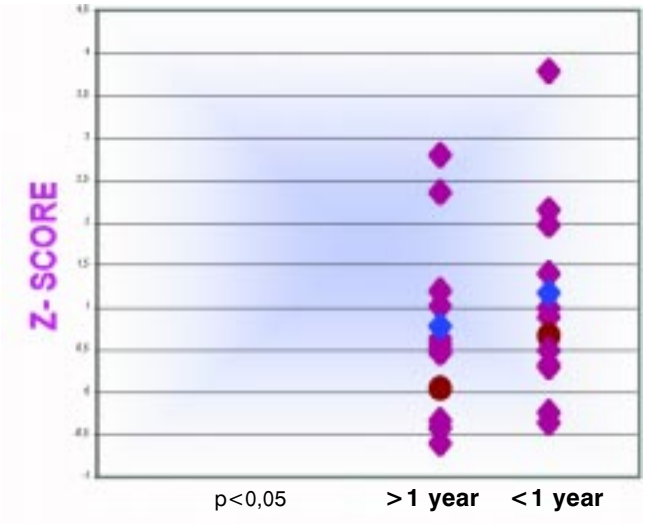

Fig. 3. Z-SCORE changes in patients >1y old and in patients <1y old

HEN can be beneficial to children with severe pulmonary or cardiac dyspnea, who often have to choose between breathing and eating.[9,10] However, in our case the patient did not comply with the HNS program, making it difficult to draw conclusions. Enteral nutrition (elemental, semi-elemental or polymeric diet) remains a mainstay of treatment for inflammatory bowel diseases such as Crohn's disease because it improves growth velocity, corrects nutritional deficits, has anti-inflammatory effects, heals mucosal inflammation and stimulates growth.[11] Recent evidence suggests that by continuing supplementary enteral nutrition after disease remission, relapse can be delayed and linear growth is improved.[12] In the present study the IBD patients were enrolled in the HNS program as part of their standard treatment after disease remission with encouraging results both in terms of nutritional status as well as disease remission. Patients with chronic metabolic disorders can suffer from severe anorexia and secondary malnutrition. Home enteral nutrition can be beneficial to them also.[10] For patients with congenital metabolic disorders included in this study HNS was the only way to adjust their food intake to their specific needs, which were very thoroughly calculated and monitored. The treatment of patients with cystic fibrosis using long-term nocturnal enteral feeding via a gastrostomy is a good and well-tolerated method, resulting in significant improvement in nutritional status and stabilizing pulmonary function.[13] Richter et al[14] reported an increase in the weight-for-height value while FEV_1 remained stable. Similarly, Ramage et al[15] reported on the efficacy of supplemental feeding in infants and children receiving Chronic Peritoneal Dialysis (CPD). They found no change in z -score for height (the decline in height was arrested) but a significant increase in weight z score, in all age groups (infants and children). Mean z score for height and weight also improved in another group of children on CPD along with the Body Mass Index.[6]

Unlike previous references,[6] this study failed to document any relation between the duration of HNS for every patient and the improvement of nutrition parameters recorded.

HNS is the alternative solution to lengthy hospitalizations when long-term nutritional support is necessary. It has been proven an effective and safe method, which leads to the best possible quality of life. Safety issues that challenged our program were closely related to the lack of experience relevant to HNS by the caregivers working with these patients at their home place, most times hundreds of kilometers away from the hospital. Complica-

tions, although severe, were never life threatening except for the mechanical one which was a J- shape misplacement of nasogastric tube. There were no cases of solution contamination. Retrograde contamination of the gastrostomy feeding system occurs frequently. Therefore, the preferential use of closed enteral feeding systems is recommended for home-based enteral nutrition programs.[16] Patchell et al[17] examined the effects of improvements in the enteral feeding protocol on bacterial contamination. They concluded that the rates of contamination were reduced significantly from 62% to 6% of feeds given at home.

Home artificial nutrition is an expensive technology but it is life saving for many patients. The only possible alternative to home treatment is keeping patients in hospital, and cost-benefit studies have demonstrated that home nutrition is about 70% more cost-effective than hospital based therapy,[3,10] The financial cost of the management of a malnourished patient has been reported to be 50% greater than that of a well-nourished patient mainly due to a longer hospital stay and a greater cost per day. The benefits of nutritional support have been reported to be a reduction in complication rate and, therefore in shorter hospital stay, and a reduced cost per day.[6]

This pilot program pointed out the necessity of introducing a multidisciplinary Nutritional Care Team (NCT) in children's hospitals as well as the need for a network of experts to support the needs of remote patients. The contributions of an NCT that will design a 'clinical pathway' are various and are of extreme importance.[6,18,19] The responsibilities of an NCT include defining the aims of nutritional support in cooperation with the requesting clinician, as well as the best way of introducing the feeds and the type of feeds required. Ireton-Jones et al[19] report that 'clinical pathways' provide standardized care for patients receiving nutritional support at home, which helps eliminate or reduce variances in treatment protocols).

Psychological preparation of children undergoing enteral nutrition is essential. Talking to a nurse and play therapist can be beneficial during the preparation and implementation of the HNS program. Children, most of the times, are part of a family, and often parental and sibling needs must be included in plans for support since the passage of a nasogastric tube is very distressing to all.[21] Mothers and family caregivers with children fed enterally at home, reported that psychosocial situations were perceived as causing a greater burden and greater difficulty in coping with everyday life.[20,21] It is recommended that the caregivers should receive appropriate education, including periodic reassessment of knowledge and skills in order to ensure the quality of care.[5] Regular monitoring of patients in order to assess their growth and ensure good tolerance of enteral nutrition needs improved coordination and cooperation between hospital and community services.[2,22] During the first weeks after discharge it is essential for patients to be more intensively monitored by dietitians since many patients tend to drop out from the HNS program when facing logistical problems.[22,23] In the present study a rather unacceptable percentage of drop out was observed. The main reasons for this were: a) the long distance that patients had to travel in order to comply with their scheduled appointments for monitoring b) the difficulties with logistical problems and c) the lack of appropriate psychological preparation and support during this pilot program.

In conclusion, most pediatric patients benefit from the HEN program in both their nutritional status and clinical condition. Complications, which are rare, hamper the growth velocity during HNS. HEN is feasible and effective, in the management of serious chronic diseases in pediatrics.

Continuous improvements towards the implementation of standards of practice, especially as far as caregiver support and patient monitoring are concerned, are expected to improve the effectiveness of HEN which represents an important part of the care for pediatric patients.

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