
Review Article

Home enteral nutrition and organizing models. Organization and risks of pediatric home enteral nutrition

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ABSTRACT: Home enteral nutrition (HEN) is the only possible alternative to staying in hospital for patients with malnutrition due to several diseases. In pediatric patients HEN is usually requested by the specialty medical team or by the general pediatrician. The nutritional team, pediatrician, home care staff, and hospital specialists collaborate to give the patient effective treatment. When dealing with malnourished pediatric patients we must consider both their metabolic and anabolic needs. In HEN-related risk management, the nutrition method, device handling, nutritional products, mechanical and septic complications must be considered. With "Taking Charge" the child on HEN and his or her family are provided with training in feeding-tube management, pumps and nutritional products, and they are controlled by a team of doctors, nurses and dieticians (control of nutritional status, treatment of complications, medications, replacement of devices, evaluation and correction of the diet, etc.) through outpatient visits, admission to day hospital and, if necessary, home visits. The benefit for the family of the child on HEN assisted in the manner of "Taking Charge" is to have a single point of reference for both medical and dietary advice and for the supply of products and devices. It ensures a better quality of life not only to the patient but also his family. (Nutritional Therapy & Metabolism 2008; 26: 32-5)

KEY WORDS: Artificial nutrition, Enteral nutrition, Nutritional team

INTRODUCTION

Home enteral nutrition (HEN) is the only possible alternative to staying in hospital for patients who need artificial nutrition. HEN is indicated for patients with malnutrition due to diseases that do not allow appropriate and sufficient natural nutrition (1). It can reduce the length of hospital stay by 70%. HEN is a type of nutritional support whose use is increasing because it improves the nutritional status of the patient with a lower cost and a better quality of life of patient and family than enteral nutrition in the hospital. Artificial nutrition is administered by a nutritional team. The team of our center is composed of a surgeon, a pediatrician, a nurse, a dietician and a pharmacist. In pediatric patients, HEN is most often requested by the specialty medical team that cures the main disease of the child. Occasionally it may be requested by the general pediatrician (2-4). Physicians of specialist centers usually turn to the nutritional pediatric team for new patients with ongoing or expected dysphagia. Furthermore, pediatricians may require HEN for patients with chronic illnesses who develop malnutrition (5, 6).

When dealing with malnourished pediatric patients,

we must consider both their metabolic needs related to the underlying disease and their anabolic needs. Before starting HEN, we must assess the home environment of the child and make it suitable for artificial nutrition. Parents and other relatives must be trained in nutritional techniques. If the child is to be fed during school time, the school staff must receive training as well. A brochure describing the most common events that may occur is useful for the family, the pediatrician and the staff of the home care unit, if present. Such a brochure is also helpful to standardize care and nursing. A phone number is generally provided to answer any questions that may arise.

It is advisable that all specialists (nutritional team, pediatrician, home care staff, hospital specialists) collaborate to give the patient efficacious treatment. Choosing the most suitable enteral nutrition technique (nasogastric, nasoenteric, transcutaneous gastric or enteral feeding tubes) as well as the most appropriate nutritional products requires the collaboration of all caregivers (relatives, pediatrician, etc.). The following factors should be taken into consideration:

- the expected duration of HEN;
- the main disease causing malnutrition (neurological, neoplastic, metabolic, cardiac, renal, etc.), because this

- may influence the choice of nutritional products;
- the patient's clinical condition and initial nutritional status (degree of dysphagia, gastroesophageal reflux, aspiration pneumonia, etc.);
- the home environment and the caregivers' background.

In HEN-related risk management, the nutrition method, device handling, nutritional products, and mechanical and septic complications must be considered. Nasogastric and nasoenteric feeding tubes should be used for short-term artificial nutrition (lasting less than 1 month). These devices are often poorly tolerated, may be accidentally removed, and can move into the bronchial tree, causing sores and gastroesophageal reflux; they may also lead to sinusitis and otitis (7).

In most cases a percutaneous endoscopic gastrostomy (PEG) is performed. The use of PEG is especially recommended in patients who need enteral nutrition at home for a period longer than 4 weeks. In some cases a surgical gastrostomy is necessary. When severe gastroesophageal reflux is present, a gastrojejunal device can be placed (by the "PEGJ" technique) combined with acid suppression and administration of prokinetic drugs before surgery (open jejunostomy, esophagogastric disconnection) (8, 9).

Local infectious complications occur most frequently in the first 2 or 3 weeks after device insertion but they may also happen later (10). Noninfectious complications like gastric mucosa exstrophy, granuloma formation or buried bumper syndrome may also occur.

In the management of clinical risks for HEN patients we should also consider the products used for nutrition and their rate of administration. An excessive administration rate can induce gastroesophageal reflux or episodes of vomiting or produce a "dumping" effect. A product with excessive osmolarity may cause enteric disorders resulting in hydroelectrolytic imbalance. The use of natural foods prepared at home may provide insufficient nutritional support or cause enteritis due to the presence of bacteria.

According to the model implemented by the Region of Tuscany, patients receiving home artificial nutrition (HAN) can be helped with the "Taking Charge" by the nutritional team. The legislation on HAN in pediatric age was implemented in June 2001, after a draft law in December 1997. In Tuscany there are 12 nutritional teams, one for each Local Health Board (LHB), and one regional pediatric nutritional team that assists HEN-assisted pediatric patients from the region (11). Doctors of the staff also provide consultation for pediatric inpatients and outpatients all around the Region of Tuscany. Our team is composed of the same staff working in the Pediatric Nutritional Unit located in a third-level pediatric hospital. In

our experience, the same nutrition support service team arranges the transition from hospital to home for those patients who need to continue therapy in the long term. However, in settings where there is no nutrition support service that coordinates the discharge from hospital, a "case manager" may be given this responsibility. A service provider delivers the required nutritional products as well as nutritional devices (syringes or nutritional pump with accessories) used for their administration directly to the patients' homes. The provision of supplies directly by the nutritional team allows to control their proper use, for the correct indications and with the correct quantity of supplements.

With "Taking Charge" the child on HEN and his or her family are provided with training in feeding-tube management, pumps and nutritional products, and they are controlled by the team of doctors, nurses and dieticians (control of nutritional status, treatment of complications, medications, replacement of devices, evaluation and correction of the diet, etc.), through outpatient visits, admission to day hospital and, if necessary, home visits.

We must remember that according to the mission of the Pediatric Nutritional Team of the Tuscany Region an important role in the transition from hospital to home is also played by home parenteral nutrition (HPN).

The undeniable benefit for the family of the child on HEN assisted in the manner of "Taking Charge" is to have a single point of reference for both medical and dietary advice in the supply of products and devices, freeing the families from the need to go to different places like pharmacies and stores that may be distant from one another. It ensures a better quality of life not only to the patient but also to his family (12).

We presented to the families of patients followed by the pediatric nutritional team an open questionnaire to assess their appreciation of the service provided and to compare the service offered by the team with the previous situation. We also asked for opinions and ideas to improve our service.

Pediatricians have varied and diverse attitudes towards the families of their patients but in most cases they have shown interest and cooperated well with the nutritional team.

The Homecare Service does not seem to work the same way throughout the Region. According to the answers to the questionnaires, some LHBs provide excellent support to the families held in close contact with the team, in others cases deficiencies have been reported.

Direct supply by the nutritional team of materials and products that spare families the need to travel periodically to pharmacies and the warehouses of the LHB are usually appreciated.

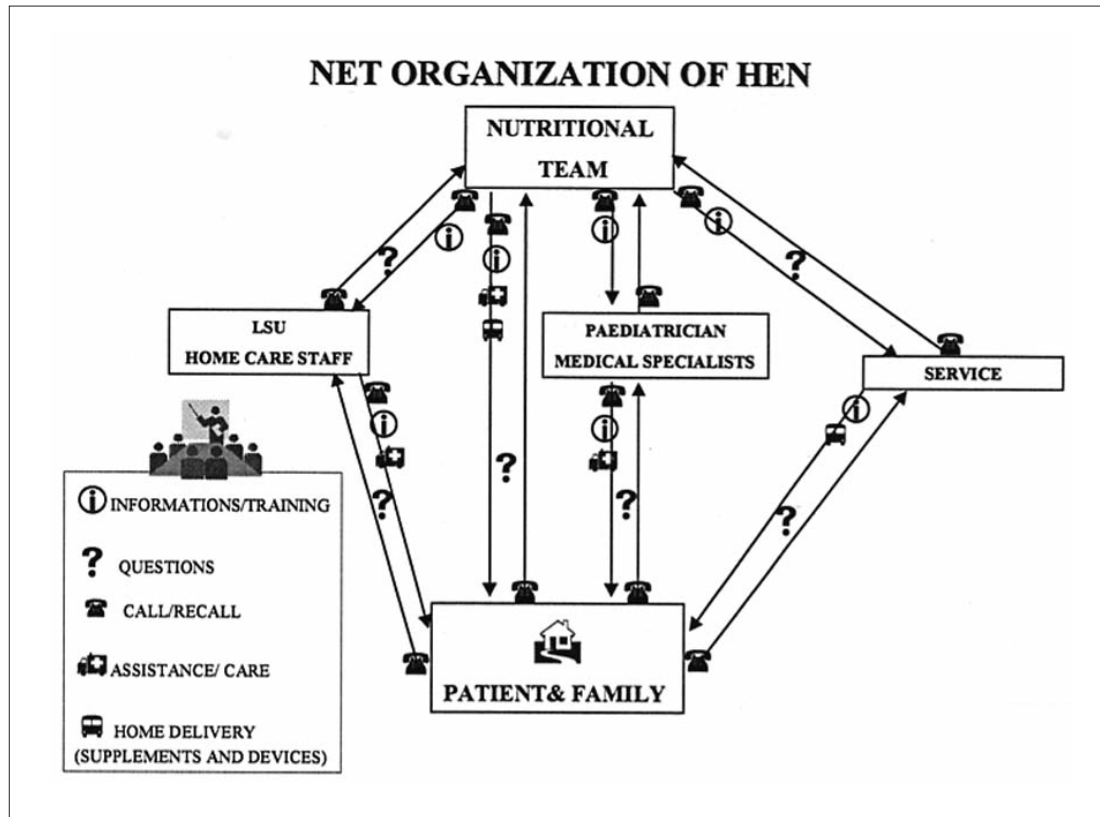


Fig. 1

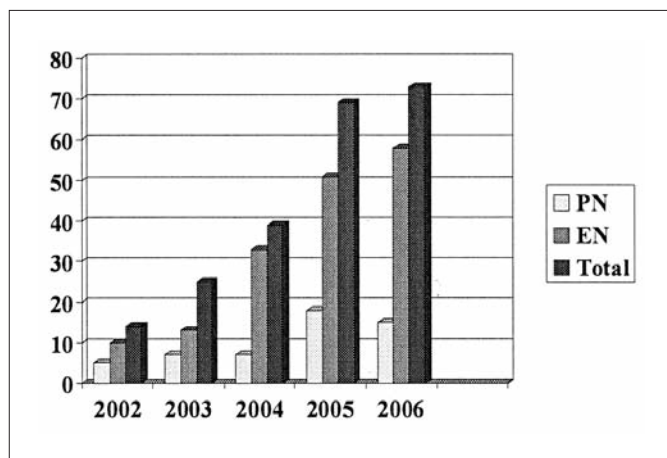


Fig. 2 - Nutritional paediatric team of the Region of Tuscany: activities in home artificial nutrition by the foundation to 2006.

Information about problems related to artificial nutrition as well as training in how to use materials and products for HEN are generally well accepted. Much appreciated also is the availability of the team operators, who can be phoned for any doubt or need.

RESULTS

The staff of the Regional Pediatric Nutritional Team of Tuscany also organizes and performs HPN. During the period 2002-2006, the number of children on HEN increased from 10 to 58, and the number of children on HPN increased from 5 to 15 (Fig. 1). Complications were recorded and classified as serious or minor. In the first group we reported a case of peritonitis in 2006, an abdominal wall abscess all around the gastrostomy in 2006, and an intragastric buried gastrostomy in 2005. There were 5 cases of aspiration pneumonia with concomitant gastroesophageal reflux. Among the minor complications there were 8 cases of gastric metaplasia granulation tissue around the gastrostomy from 2004 and 5 cases of accidental tube dislodgement, intragastric in 3 cases and extruded in 2. Gastrostomy tube obstruction was considered a minor complication that could be treated at home by the caregivers. Complications related to HPN are not treated in this paper.

CONCLUSIONS

The only possible alternative to home treatment is keeping pediatric patients in hospital. Although home

nutrition is usually considered by children and families to lead to an improvement in their quality of life, the complications of these techniques have to be carefully assessed and prevented. Enteral (and parenteral) nutrition therapies are routinely used in the acute care setting, in hospital, and in home care for pediatric patients who are unable to ingest or absorb adequate nutrients orally.

It is therefore appropriate to deal with issues related to the clinical risk:

- with the patient and his family
- with the pediatrician
- with the medical specialists who treat the underlying disease
- with the Homecare Service Team.

The advantages of teamwork include:

- control of resources (sending materials and products according to actual needs)
- provision of a single reference point for the family
- quick solutions to any nutritional problem.

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