

Original

Home enteral nutrition in children; a 10 year experience with 304 pediatric patients

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Abstract

Background & aims: Home enteral nutrition is used increasingly in pediatric populations. Our objective was to describe the profile of pediatric patients requiring this treatment.

Material and methods: All patients under 18 years old requiring treatment with home enteral nutrition between January 1995 and December 2004 were analyzed retrospectively.

Results: 304 patients were studied (157 boys). The mean age at the start of treatment was 4.02 ± 4.09 years, median of 2.5 years; 28% of all patients were under 1 year. The main indications were oncological disease in 91 patients (29.9%) and digestive diseases in 84 (27.6%). There were significant differences depending on the clinical diagnosis for the start age, type of access, infusion regime and formula prescribed. Nutrients were delivered by nasogastric tube in 218 patients (71.7%). Overnight enteral nutrition was the preferred infusion regime in 155 patients (51%). Adult or pediatric polymeric formulas were mostly prescribed in 190 patients (62.5%). The mean treatment duration was 306 ± 544 days.

Conclusion: In our series, enteral support usually begins at an early age. Its characteristics varied depending on patient pathology. Knowledge of the pediatric patient profile is important to design the most effective strategy for home enteral nutrition.

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Key words: *Home enteral nutrition. Children. Enteral tube feeding. Gastrostomy. Jejunostomy.*

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NUTRICIÓN ENTERAL DOMICILIARA EN NIÑOS; 10 AÑOS DE EXPERIENCIA CON 304 PACIENTES

Resumen

Introducción y objetivos: La nutrición enteral domiciliaria es un soporte nutricional cada vez más utilizado en población pediátrica. Nuestro objetivo ha sido describir el perfil de un grupo de pacientes pediátricos que precisaron este tratamiento.

Material y métodos: Se analizaron retrospectivamente todos los pacientes menores de 18 años que precisaron tratamiento con nutrición enteral domiciliaria entre enero 1995 y diciembre 2004.

Resultados: Se estudiaron 304 pacientes (157 niños). La edad media al inicio del tratamiento fue de 4,02 ± 4,09 años, con una mediana de 2,5 años; un 28% de los pacientes eran menores de 1 año. Las indicaciones principales fueron la enfermedad oncológica en 91 pacientes (29,9%) y la digestiva en 84 (27,6%). Se encontraron diferencias significativas en función del diagnóstico clínico para la edad de inicio, el tipo de acceso, el modo de administración y la fórmula prescrita. El tipo de acceso más utilizado fue la sonda nasogástrica en 218 pacientes (71,7%). El régimen de infusión más utilizado fue la nutrición enteral nocturna en 155 pacientes (51%). Se prescribió principalmente fórmula polimérica de adultos o pediátrica en 190 pacientes (62,5%). La duración media del tratamiento fue de 306 ± 544 días.

Conclusión: En nuestra serie, el soporte enteral suele iniciarse a edades muy tempranas. Sus características variaron en función de la patología del paciente. Conocer el perfil del paciente pediátrico es importante para diseñar la estrategia más eficaz en el uso de la nutrición enteral domiciliaria.

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Palabras clave: Nutrición enteral domiciliaria. Niños. Nutrición enteral por sonda. Gastrostomía. Yeyunostomía.

Abbreviations

EN: Enteral nutrition. GT: Gastrostomy.

HEN: Home enteral nutrition.

JA: Jejunal access. NGT: Nasogastric tube

Introduction

Enteral nutrition (EN) is the preferred technique for artificial nutritional support. It consists of administering nutrients through the digestive tract using a defined mixture (enteral formula), generally by means of nasogastric tube or tubes placed directly through a stoma. It also includes the supply of natural food stuffs using these artificial accesses.²

Since its application at the onset of the 1970s,³ the use of EN has continued to grow thanks to, among other factors, improved knowledge of patient nutritional needs, the appearance of new enteral formulas, improved healthcare support materials, enhancement in the approach and nutritional infusion techniques and the design of multidisciplinary protocols to reduce complications and evaluate the results.¹

Home Enteral Nutrition (HEN) is the prolongation of enteral nutritional support at the patient's own home. This support was previously established in the hospital, and whose control is carried out by the healthcare team at the hospital center or at the patient's own home. The general objectives of HEN seek to stabilize the base illness, shorten hospital stays and allow the child to integrate into his/her family and social environment, which translates into improved quality of life for the child⁴ and a decrease in treatment costs.⁵

Despite the increase experienced by HEN in pediatric patients in recent years, publications on this topic are scarce. This study analyzes the profile of a group of pediatric patients who required HEN in a 10-year period, according to the variables of age, indication, type of enteral access device, infusion regime and nutrients delivered.

Patients and methods

A total of 304 patients (157 boys) were studied. The data of all the patients under 18 years old who required HEN from January 1995 to December 2004 in a tertiary hospital was analyzed retrospectively. The study protocol was approved by the Hospital Ethics Committee, in accordance with the Declaration of Helsinki of 1964, revised in Seoul in 2008.

The data collected included age, gender, indication, type of enteral access, infusion regime, nutrients delivered and duration of the support. HEN indications were classified as oncological disease, digestive disease, neurological disorders, failure to thrive, and miscella-

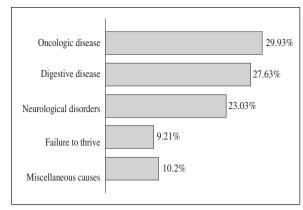


Fig. 1.—Pathologies which led to HEN.

neous causes (fig. 1). Nutrients were delivered by nasogastric tube (NGT), gastrostomy (GT) or jejunal access (JA). NGT was used when the foreseen duration of the nutritional support was less than 3 months or when GT was contraindicated or rejected by the parents or patient. GT was used when the foreseen duration exceeded 3 months or placement of NGT was not possible. Four infusion regimes were used: continuous EN (> 16 hours/day), overnight EN (< 12 hours/day), day time bolus EN and day time bolus with overnight EN. For continuous or overnight EN, peristaltic pumps were used (Frenta System III®, Fresenius; Companion®, Abbot). Enteral nutrition formulas used during the study included standard infant formulas, hydrolyzedprotein formulas, polymeric adult-type and polymeric pediatric formulas. These products were adapted to the age and diagnosis of each patient. Standard infant and hydrolyzed protein-based formulas may have eventually been concentrated or enriched with carbohydrate and/or fat units.

Statistical analysis

First, the descriptive statistics, means and typical deviations among the quantitative variables were calculated, as well as frequencies and percentages among the qualitative variables. For the comparisons between groups, F de Fisher-Snedecor was used for quantitative variables and the relationship between simple variables was analyzed using X^2 for categorical variables. For statistical analysis we used the *Statistical Package for the Social Sciences (SPSS)*, version 16.0. For all the tests carried out, bilateral statistical significance was set at p < 0.05.

Results

Population

The mean age of patients commencing HEN was 4.02 ± 4.09 years (Q1-Q3: 0.83-6.16) with a median of

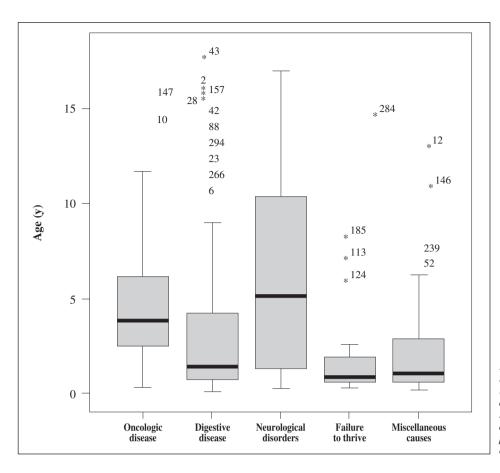


Fig. 2.—Age of patients at the beginning of home enteral nutrition according to individual pathology. t = 3.088, p = 0.003- this age distribution according to pathologies reached statistical significance.

2.5 years; 28% of the patients were under 1 year old. The age varied from 2.6 ± 3.2 years in patients with failure to thrive and 5.9 ± 5.0 years in patients with neurological disorders. The differences in the start age, depending on clinical diagnosis, were statistically significant (F = 8.292, p = 0.001) (fig. 1). The mean age of the patients HEN concluded was 4.8 ± 4.4 years.

The mean duration of the HEN was 306 ± 544 days (range 3 - 3565): 81 patients (26.6%) received HEN for less than 30 days and 11 patients (3.6%) for more than 5 years. The differences in the time with HEN depending on the clinical diagnosis were statistically significant (F = 8.175, p = 0.001). At the conclusion of the study, 42 patients (13.8%) continued with the support; in 190 patients (62.5%) normal oral feeding was restored, 32 patients died (10.5%); there was failure of HEN in 20 (6.6%) and data was not obtained in 20 (6.6%) (moved to another region).

Indications

Indications for administering HEN were oncological disease in 91 patients (29.9%), digestive disease in 84 (27.6%), neurological disorders in 70 (23.0%), failure to thrive in 28 (9.2%) and miscellaneous causes in 31 (10.2%). Miscellaneous causes included metabolopathies, cardio-respiratory, renal disease and immunodeficiency.

Of the oncology patients, 34 (37.4 %) suffered malignant hemopathies, 33 (36.3%) solid tumors and 24 (26.4%) intracranial tumors. Digestive disorders included gastro-esophageal disease in 28 patients (33.3%); cystic fibrosis in 20 (23.8%); malabsorption in 20 (23.8%), which included coeliac disease, milk allergy, short bowel syndrome or severe diarrhea; intestinal dysmotility in 7 (8.3%); inflammatory bowel disease in 6 (7.1%); and hepatic disease in 3 (3.5%). Of the neurological patients, 23 (32.8 %) presented cerebral palsy, 7 (10%) sequels to infectious disease or traumatic injury, 8 (11.4%) malformations of the central nervous system, 6 (8.6%) neuromuscular diseases, 13 (18.6%) neurodegenerative diseases, and 13 (18.6%) others.

Type of enteral access devices, infusion regime, and nutrients delivered

Enteral formula was delivered by NGT tube in 218 patients (71.7%), GT in 82 (27.0%) and JA in 4 (1.3%). There were statistically significant differences when the type of enteral access and the indication (clinical diagnosis) were considered ($X^2 = 54.111$, p = 0.001) (fig. 2). NGT was the most commonly used access in most of the diagnoses except in patients with neurological pathology; in this type of patient GT was preferred.

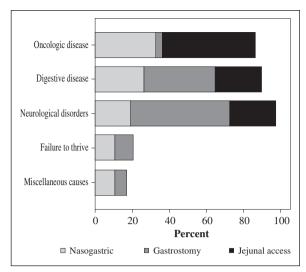


Fig. 3.—Type of enteral access devices according to the individual pathology. $X^2 = 31.349$, p = 0.001- the differences found between routes of administration according to individual pathologies reaches statistical significance.

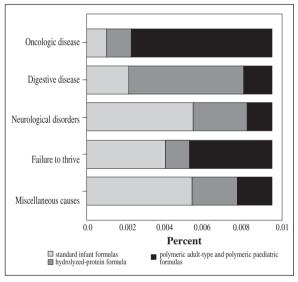


Fig. 4.—Types of formulas prescribed according to the individual pathology. $X^2 = 100.662$, p = 0.001- the differences found between types of formulas according to individual pathologies reaches statistical significance.

Infusion regime was continuous EN in 64 patients (21.1%), overnight EN in 155 (51%), day time bolus EN in 34 (11.2%) and day time bolus with overnight EN in 51 (16.8%). There were statistically significant differences when the administration method and the indication (clinical diagnosis) were considered ($X^2 = 54.476$, p = 0.001) (fig. 3). All patients with continuous or overnight EN used a pump. For bolus EN both pump and syringe were used.

The nutrients delivered during the study period comprised standard infant formulas in 50 patients (16.4%), hydrolyzed-protein formulas in 64 (21.1%) and polymeric adult-type and polymeric pediatric for-

mulas in 190 (62.5%). Standard infant formulas and hydrolyzed-protein formulas were, for the most part, powdered and were reconstituted by the parents according to the instructions given in writing in the time of discharge. Standard infant formulas were generally prescribed for patients with neurological disorders in 13 patients (26.0%) and patients with digestive disease in 12 (24.0%). Hydrolyzed-protein formulas were especially indicated for patients with digestive disease in 41 patients (64.0%). Polymeric adult-type and polymeric pediatric formulas were prescribed mainly for patients with oncological disease in 83 patients (43.6%) and patients with neurological disorders in 52 (27.3%). The differences found between types of formulas, prescribed according to indication, reached statistical significance ($X^2 = 100.662$, p = 0.001) (fig. 4).

Discussion

The studies into pediatric patients with HEN are scarce, although recently, Daveluy et al.⁷ Diamanti et al.⁸ Salomon and Garbi⁹ as well as Szlagatys-Sidorkiewicz et al.¹⁰ have published their experiences on this topic. Comparison between the various series is difficult since the itemized classification of the pathologies varies from on study to another, as well as the type of diseases cared for at the various hospitals and the peculiarities of the healthcare organization of each country or region.

It is important to point out that this series is the most important research carried out in Spain with pediatric patients with HEN. To date, publications about HEN from the NADYA-SENPE group (Out-patient and home enteral nutrition and of the Spanish Parenteral and Enteral Nutrition Society) from the year 1993¹¹ up to 2009¹² include an extremely limited number of pediatric patients.

The age of patients in this study was 4.0 ± 4.09 years, with a median of 2.5 years similar to those in the study by Salomon and Garbi⁹ $(4.11 \pm 4.5 \text{ y}, \text{ with a median of }$ 2 y) and they were younger than in the study of Daveluy et al. (5.4 ± 5.3) y, with a median of 3 y) and that of Szlagatys-Sidorkiewicz et al.¹⁰ median age 6 y (range 0.75-18 y) In the Planas et al. 13 study, the median age of the patients under 14 years with HEN was 6.0 ± 4.3 years, older than this study. That the patients are younger in this study could be due, in part, to the incorporation of nutritional care as a part of the general health care for the early detection and prevention of malnutrition during the hospitalization of chronic patients, especially in oncological patients, for the survival of newborns with special medical and nutritional needs,14 the creation of a nutritional support team,15 and the development of the gastrostomy techniques in small children.16 The age of the patients, on the other hand, varies greatly according to the individual pathology. In this study, the youngest patients were those who were failing to thrive, while the oldest were the patients with neurological disorder. In the study by Daveluy et al.⁷ the youngest patients were those with hepatic disorders and the oldest were those with inflammatory bowel disease, while in the study by Salomon and Garbi⁹, the patients with a milk allergy were the youngest and those with cerebral palsy were the oldest, as in this series.

The most frequent pathology in this series was oncology (30%), which only represents 1.5%, 11% and 1% of the broader series^{7,8,9} followed by digestive disease (27.6%) and neurological disorders (23%). These last two pathologies are the more common in the works published. Digestive disease represent 29% in the study by Holden et al.,4 44% in the Diamanti et al.8 study, 35% in that by Daveluy et al.7 and only 9.6% in the study by Szlagatys-Sidorkiewicz et al.¹⁰ This is due to the characteristics of this hospital, since it is a reference hospital in the treatment of pediatric oncology patients. In the study with adults by Pironi et al.17 the greatest prevalence of HEN was observed in oncological patients and in pediatric patients, the greatest prevalence was in neurological cases. The most frequent digestive disease in this study was gastroesophageal disease, followed by the cystic fibrosis and malabsorption; similar results were obtained in the study by Daveluy et al. 7 while in the study by Diamanti et al.8 the main causes of digestive disease was malabsorption followed by gastroesophageal reflux. In the study by Salomon and Garbi⁹, it was cystic fibrosis followed by malabsorption.

In this study, NGT was the most frequent access in comparison to a stoma; similar results were reported by Daveluy et al.7 and Diamanti et al.8. This agrees with the observations in the BANS register¹⁴. This is due to the fact that gastrostomy is usually proposed over long periods of time. Some authors indicate that even in short periods of time, gastrostomy may be indicated18-20; this period could be reduced greatly in the most recent recommendations by ESPEN²¹ (2-3 weeks) and by ESPGHAN²² (4-6 weeks). Despite these recommendations, all the studies, except that by Szlagatys-Sidorkiewicz et al.¹⁰ (most patients had neurological problems and a high mean age) carried out with children, had a higher frequency of nasal routes. This may be due to the fact that these patients require short periods of HEN or who present transitory processes (eg, cancer, as in this series), awaiting a treatment that will resolves their disease (heart surgery), or until landmarks of maturity are reached to allow them to completely recover oral feeding. Gastrostomy is unavoidable in the cases of interrupted esophagus and is of great use in cases of dysphagia. In this series, the use of gastrostomy (27.0% of the total) was lower to what was expected, as, strictly applying the criteria of duration (> of 3 months), this access technique should have been used on 42% of these children. These results are inferior to those of the series by Diamanti et al.8 who carried out gastrostomy in 38% and lower to the data presented by Daveluy et al.7 who carried out gastrostomy in 47%. There are multiple reasons to not use gastrostomy in more cases: pathologies in which it is contraindicated (hepatic alterations due to transplant); technical difficulties due to anatomical changes (certain patients with infantile cerebral palsy); prior surgeries or massive hepatomegaly; due to indication by the doctor to prevent medical and psychological complications and above all, due to medical-cultural, family and social factors. In this regard, the reflections by Gauderer¹⁶ are revealing, because they show the need for the patient and their environment to be convinced about using the technique. In this series, gastrostomy was the most used access in patients with neurological disease (54.3%), which usually requires HEN for longer period of time. Jejunal access constitutes an exceptional option both in this case and in other series.7-10 Indicated in cases of severe RGE, gastric dysmotility and pancreatitis, its use in children has major technical difficulties. It was used in the last two pathologies.

In this study, the most used infusion regime was overnight EN in 51% of the total series; in these cases, the application of the enteral serves to complete the child's oral feeding, which occurs above all in patients with failure to thrive and digestive pathology. as opposed to people with neurological disease. This is due to the fact that children with failure to thrive or digestive disease are less deteriorated and the indication of overnight EN is to try to preserve oral feeding during the day and avoid dysfunctions of alimentary behavior secondary to the use of the tube. These results could not be compared with the previous series because this variable was not included in these studies. Peristaltic pumps were used for continues administration in all the children, thus assuring better compliance with the prescription, tolerance of the EN, and comfort and tranquility of the family in the nocturnal infusions. This is an extreme that is not clear in other series, 7,8 since the reference to the use of a pump is made globally.

Regarding the prescription formula, the most prescribed product in this study was polymeric formulas, followed by hydrolyzed-protein formulas and standard infant formulas. The pediatric and adult polymeric diets are contemplated jointly because the criteria to indicate one or the other has changed while the study was undertaken (initially adult diets were indicated starting from the age of 6 years and later starting from 10).^{1,23} Also, the study fails to analyze whether the formula was supplemented with fiber or whether they were hypercaloric preparations, since pediatric products with these characteristics were unavailable in Spain until after the year 2000.² Specific indications for certain pathologies such as hypercaloric presentations in malnourished oncological patients²⁴ or products with fiber in children with neurological disorders²⁵ must be considered in practice.

The formulas indicated in these patients were prescribed bearing in mind their age, their digestive function and the existence of specific nutritional needs. 1.2 In some groups of patients, the type of formula varied over time, such as the case of cystic fibrosis 26 (in which hydrolyzed diets are currently destined to those cases of seriously malnourished infants in the first phases of their nutritional rehabilitation, with short intestine or allergy to cow milk proteins), and in inflammatory bowel disease (in which case the polymeric diets reach the same nutritional and therapeutic objectives as hydrolyzed or elemental diets). 27

With the exception of the polymeric diets, the rest of the types of formulas used and the supplements with modular nutrients (carbohydrate and/or fat), were presented as powder and were prepared by the parents following the instructions given in writing in the time of patient hospital discharge as well as to composition, hygienic measures and change of systems, this latter performed daily. It is unknown (because it was not object of this work, nor has it been researched routinely) whether these products could have been contaminated, as has been described by other groups. Currently, some preparations are presented as liquids, ready to use, which constitutes a great advance from the point of view of safety and ease of handling.

One limitation of this study is that the patients come from a single hospital, which does not allow studies to be made of either prevalence or incidence of HEN. Another limitation is that there is no data about complications in the patients or hospital readmissions. A new data protocol has been developed to incorporate new patients and include data from other hospitals.

Conclusion

Over a 10 year period, a large group of pediatric patients at a tertiary hospital diagnosed with variety of chronic diseases was treated with HEN. This type of treatment can be carried out at early ages and can be prolonged over variable periods of time, even years.

The access route must be suited to the clinical diagnosis and the duration of the support, but the factors of the patient's environment must also be considered. The doctor must individualize the indication and provide the patient with the best treatment.

The existence of numerous types of formula and HEN infusion regimes allow the support to be adjusted to individual patient needs and requirements.

This is the first national study in Spain to include pediatric patients with HEN in which the profile of the pediatric patient requiring HEN is described according to age, indication, type of enteral access, infusion regime, and type of formula prescribed. New studies within Spain are needed, which allow effective and safe strategies for pediatric patient with HEN to be designed.

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