

Home enteral nutrition in children: a one-year experience with 184 patients in Distrito Federal, Brazil

Ana Lúcia Ribeiro Salomon Zaban and Maria Rita Carvalho Garbi Novaes

Human Nutrition Post Graduation Program, Faculdade de Ciências da Saúde, Universidade de Brasília, Brazil

Corresponding author: Ana Lúcia Ribeiro Salomon Zaban, SQS 102 – bloco ‘G’ – apto. 201, 70.330-070 Brasília, Distrito Federal, Brazil. Emails: ana.salomon@gmail.com, anasalomon@ig.com.br

Abstract

There is little published evidence concerning home enteral nutrition therapy in children. The present work attempts to analyze the profile of pediatric patients undergoing this therapy in the Federal District, Brazil. This is a retrospective study of data of all patients younger than 18 y old enrolled in the Home Enteral Nutrition Therapy Program of the Brazilian Public Health Department, Federal District, from January to December 2005. The study covered 184 children and adolescents. The patients' median age at the beginning of treatment was 2.00 y (Q1–Q3: 1.00–7.00). Pathologies leading to home enteral nutrition therapy were digestive disorders (54.9%), neuromuscular disorders (21.2%), epidermolysis bullosa congenital (7.1%), congenital malformation (5.0%), cardiac disorders (4.3%), malignancies (0.5%) and miscellaneous causes (7.0%). The prevalence of the therapy was 81.23. The oral route was used in 70.7% of cases. Enteral feeding comprised mainly industrial pediatric formulas (44.9%) and hydrolyzed-protein formulas (20%). This study supports the fact that home enteral nutrition is necessary in special pediatric conditions, favoring a precocious hospital discharge and then lowering the risk of infectious processes, and stimulating the reinsertion of children in their homes, their safe environment. The need for further studies still remain, especially ones in national basis, so as to reinforce the importance of a national regulation which would benefit all Brazilian pediatric patients in need of such therapy.

Keywords: child, enteral nutrition, home care services

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Introduction

Home enteral nutrition (HEN) is a therapeutic modality applied to patients who have diseases that hinder them from receiving nutrition through the oral route, and are discharged from hospitals but need to maintain this therapy at home. Evidences support that HEN is a safe and effective therapy for children to prevent malnutrition related to chronic diseases.¹

In November 2004 the *Secretaria de Estado de Saúde do Distrito Federal* (SES/DF) – Public Health Department of the Brazilian Federal District – published the first Regulation on HEN supply, covering all users of the public health system.²

Since there is little detailed evidence published on national basis referring to home enteral nutrition therapy (HENT) in children, added to the fact that literature on this subject is scarce, the present work attempts to analyze the profile of pediatric patients undergoing this therapy in the DF, Brazil, according to the variables of age, indications,

modality of enteral access and type of formulas used for this therapy.

Materials and methods

Organizational aspects

The Brazilian Public Health Care System, *Sistema Único de Saúde*, is based on the Federal Constitution and national legislation,^{3,4} which define the general rules for Health Care Provision and Regional Health Care Systems by which the administrative regions provide health care to their residents. The administrative regions are autonomous, being able to publish their own regulations in order to better fulfill the health needs of their population, provided the regulation respects the national legislation.

The DF is a federal unit, which is divided into several health regions, 13 of which apply enteral nutrition therapy (ENT) in the hospital environment. Each region is provided with local health-care units (hospital and health centers),

which are the operative arms of the Regional Health Care System, called SES/DF.

The DF Regional Regulation² defines the type of HEN approved, the referral centers and treatment management. The HEN Program concerns patients discharged from hospitals, by request of a hospital multidisciplinary team that evaluates the patient's clinical and nutritional status, plans the nutritional therapy and runs a training course about HEN self-management for the patients or their families. The regulation also establishes that patients have to be followed up by nutritionists every three months to re-evaluate their nutritional status, adherence to HEN therapy, complications and intercurrent illnesses.

The Government of the DF is responsible for all HEN costs, providing this therapy freely for its inhabitants. The therapy includes the delivery of nutritional products and infusion sets.

Before the SES/DF regulation was published, all heads of nutrition services of the 13 hospitals and all technical sponsors for ENT were trained regarding this therapy and its good manufacturing practices. Upon publication of the regulations, meetings were held with the same crew in order to set protocols about the necessary procedures to implement HEN supply.

Data collection

A total of 184 patients were studied. Individual data on patients younger than 18 y, who entered the SES/DF HEN Program, were collected and analyzed retrospectively from January to December 2005, using a structured formulary designed by the Coordinator of the HEN Program of SES/DF. The patient group studied corresponded to 100% of all children who received HENT in DF.

HEN was defined as the administration of enteral feeding formula by the nasal route (nasogastric – NGT or nasoenteric – NET) or ostomy (gastrostomy – GT or jejunostomy – JT), including specific cases of specialized formulas through the oral route (Crohn's disease, cystic fibrosis, epidermolysis bullosa congenital [EBC] and severe food allergies).² HEN indications were classified as digestive disorders, neuromuscular disorders, EBC, congenital malformation, cardiac disorders, malignancies and miscellaneous causes.

Data were obtained from the medical and dietetic reports of all patients, stored at the Central Coordination of HEN Program in the Nutrition Department of SES/DF. Enteral nutrition (EN) utilized during the study included commercially manufactured products, categorized into six groups: industrial pediatric formula, hydrolyzed-protein formula, oral supplements, specialized adult-type diet, polymeric adult-type diet and standard infant formula. Formula prescription was based on age and clinical diagnosis. Nutrients were delivered by NGT, NET, GT or JT. Enteral feeding was administered using gravity.

Statistical analysis

Formularies were collected and analyzed by the Coordinator of the HEN Program of SES/DF. The relation between single variables was analyzed using the χ^2 test for variable category.

Significant statistics with $P < 0.05$ and a confidence interval of 95% were used for the purpose of data analysis in the study. For the χ^2 test, when more than 20% of the cells showed a value of expected frequency lower than 5, exact χ^2 test was applied. When it was not possible to use exact χ^2 test, due to the inability of the program in processing this test, Monte Carlo's χ^2 test was used, as a recommendation of the Statistic professor.

Statistical Package for Social Sciences 15.0 was used to analyze data.

Ethical aspects

The research project was approved by the Institutional Review Board (*Comitê de Ética em Pesquisa*) – SES/DF.

Results

Population

During the analysis of data concerning the year 2005, 184 pediatric patients underwent HENT. Of these, 81 (44.1%) were female patients and 103 (55.9%) were male patients. The patients' median age at the beginning of treatment was 2.00 y ($Q1-Q3$: 1.00–7.00). Ages varied from 1.9 ± 1.9 y for patients with milk allergy to 7.9 ± 5.0 y for patients with cerebral palsy (Figure 1). The age differences found according to clinical diagnosis reached statistical significance ($P = 0.0001$).

All patients followed during this study still required the therapy when data collection was concluded and remained receiving the formulas through the program. For this reason it was not possible to assess mean duration of therapy for these patients.

Indications

Indications for administering HEN were digestive disorders in 101 patients (54.9%); neuromuscular disorders in 39 (21.2%);

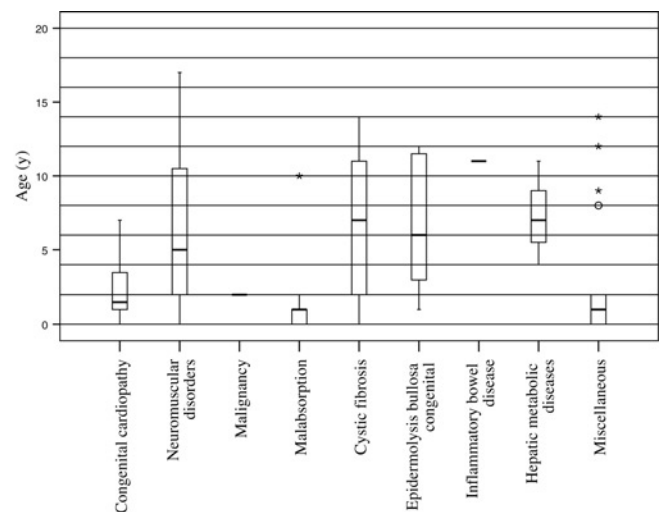


Figure 1 Age of patients at the beginning of home enteral nutrition according to individual pathology. $P = 0.0001$ – this age distribution according to pathologies reached statistical significance

EBC in 13 (7.1%); congenital malformation in 9 (5.0%); cardiac disorders in 8 (4.3%); malignancies in 1 (0.5%); and miscellaneous causes in 13 (7.0%). Miscellaneous causes included kidney disorders, diseases related to prematurity, exogenous intoxication, sepsis and failure to thrive. Digestive disorders included cystic fibrosis in 64 patients (63.4%); malabsorption in 33 (32.7%), which included celiac disease, milk allergy, short bowel syndrome or severe diarrhea; inflammatory bowel disease (1.0%); and hepatic metabolic disease (2.9%).

Prevalence of HEN

Prevalence (total cases/million inhabitants) was calculated using as reference the estimated population of DF in 2005, which was 2,277,259 inhabitants.⁵ The prevalence of HEN for children was 81.23. The most prevalent group disease among children and adolescents was digestive disorders – prevalence of 39.96. (Table 1).

Type of enteral access devices and nutrients delivered

Enteral formulas were delivered through the oral route in 130 (70.7%) patients, GT in 20 (10.9%), NGT in 20

(10.9%), NET in 13 (7.1%) and JT in 1 (0.5%). Statistical significance was found when considering the prescribed routes for EN administration and primary indication of ENT (clinical diagnosis) ($\chi^2 = 138.351$, $P = 0.011$ [0.008–0.013]), as can be observed through the following data: oral route was primarily used for patients with hepatic metabolic diseases (100%), inflammatory bowel disease (100%), EBC (100%), cystic fibrosis (93.8%), malabsorption (93.9%), congenital cardiopathy (62.5%) and miscellaneous (50%). GT was mainly used for neuromuscular disorders (43.6%) (Figure 2). Most patients in NGT, NET, GT and JT received the formulas through gravity (99.5%).

The nutrients delivered during the study period comprised polymeric industrial pediatric formulas for 83 (44.9%) patients, hydrolyzed-protein formulas for 37 (20%), standard infant formulas for 34 (18.4%), oral supplements for 15 (8.1%), polymeric adult-type diets for 7 (3.8%) and specialized adult-type formulas for 2 (1.1%). Data with regard to six patients were missing.

The polymeric formulas were mostly prescribed for EBC (100%), malignancy (100% – only one patient), neuromuscular disorders (62.16%), cystic fibrosis (55.56%) and miscellaneous (38.10%). Hydrolyzed-protein formulas were prescribed especially for malabsorption (51.61%). Standard infant formulas were prescribed mainly for hepatic metabolic disease (100%) and congenital cardiopathy (57.14%). Oral supplements were prescribed only for cystic fibrosis patients (23.81%). Specialized adult-type formulas were mainly prescribed for inflammatory bowel disease (100% – one patient) (Figure 3). The differences found between types of formulas, prescribed according to pathologies, reached statistical significance ($\chi^2 = 228.629$, $P < 0.001$ [0.000–0.000]).

Table 1 Prevalence (number of cases/million inhabitants) of home enteral nutrition (HEN) by primary disease group

Disease group	Prevalence (cases/million inhabitants)
Cardiovascular	2.63
Neuromuscular	13.17
Digestive	39.96
Malignancies	0.44
Epidermolysis bullosa	5.71
Others	19.32
Total	81.23

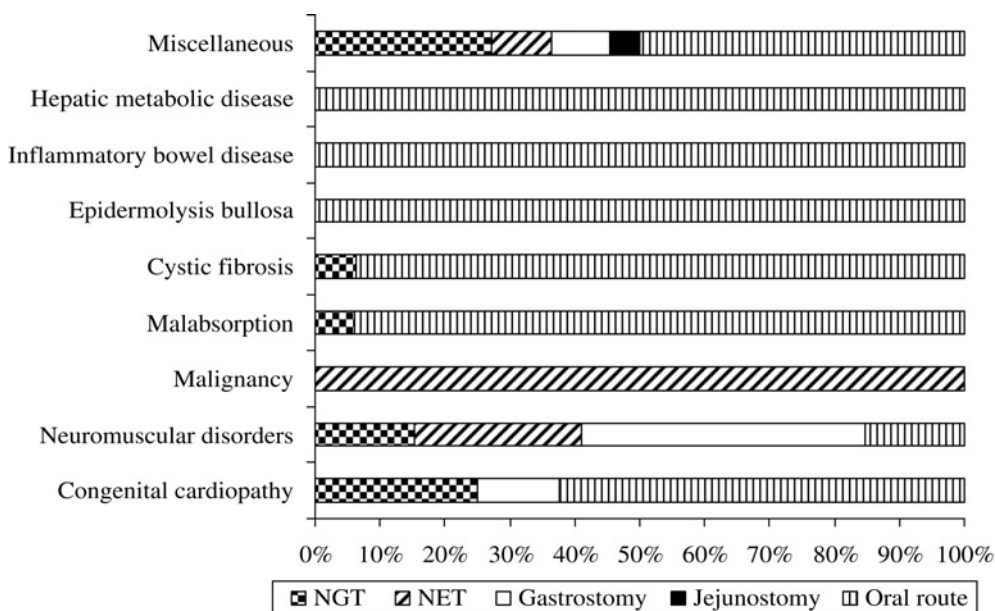


Figure 2 Type of enteral access devices according to the indication. $\chi^2 = 138.351$, $P = 0.011$ (0.008–0.013) – the differences found between routes of administration according to pathologies reached statistical significance. NGT, nasogastric; NET, nasoenteric

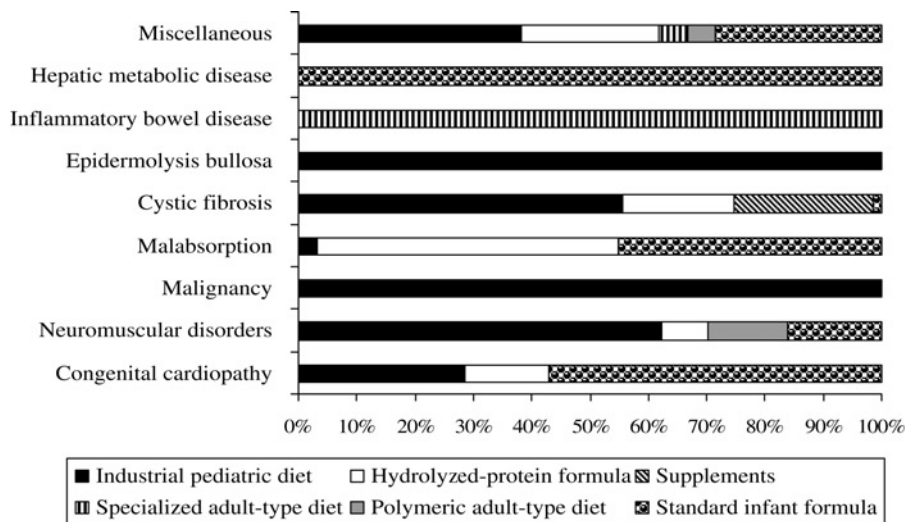


Figure 3 Types of formulas prescribed according to the indication. $\chi^2 = 228.629$, $P < 0.001$ (0.000–0.000) – the differences found between types of formulas prescribed according to pathologies reached statistical significance

Discussion

Studies on HEN in children are scarce and usually involve not only children but also adults and elders. Daveluy *et al.*¹ and Diamanti *et al.*⁶ have recently published their experience with HENT in children.

It is important to highlight the fact that this is the most complete research carried out so far dealing with HENT in children in Brazil. Until now, there have been no other Brazilian studies concerning this theme, which would allow data comparisons. For this reason, it is not possible to obtain a more detailed explanation on the specificities of this therapy in this country, besides the ones presented in this study.

Patients in this study are slightly younger when compared with those in Daveluy and colleagues' work – 4.11 ± 4.581 y (range 0–17), with a median of 2 y in the present study versus 5.4 ± 5.3 y (range 0–17.8), with a median of 3 y in the work of Daveluy *et al.*¹ In Planas *et al.*'s study,⁷ the median age for HEN patients younger than 14 y old was 6.0 ± 4.3 y, also higher than the present study. In the present study, younger patients comprised those with milk allergy, while older patients comprised children with cerebral palsy. In Daveluy *et al.*'s research,¹ younger patients corresponded to patients with hepatic disease, whereas the older ones, patients with inflammatory bowel disease.

The studies of Daveluy *et al.*¹ and Diamanti *et al.*⁶ state digestive diseases (35% and 44%, respectively) and neuromuscular disorders (35% and 34%, respectively) as main causes leading to HEN in children. Those results are similar to what is described in this work, especially concerning digestive diseases (54.9%). Neuromuscular disorders were also less frequent in this study if compared with others (21.2%). It is worth highlighting the fact that the most frequent neuromuscular disorders found in this study (cerebral palsy and chronic encephalopathy – 14.3% and 7.1%, respectively), in addition to food allergies, are

often preventable through an adequate prenatal follow-up and nutritional guidance. This reinforces the importance of primary care for patients.

The most frequent digestive diseases in this study were cystic fibrosis followed by malabsorption. In the study of Daveluy *et al.*¹ the main digestive disorders included gastroesophageal disorders followed by cystic fibrosis and inflammatory bowel disease, while in the study of Diamanti *et al.*⁶ the chief causes were malabsorption followed by gastroesophageal reflux.

According to Daveluy *et al.*¹ a comparison of repartitioning of underlying diseases with the literature is difficult because pathologies are not always characterized the same way in other studies.

The results between the works of Pironi *et al.*⁸ and the present study (data on the whole population) are similar as far as prevalence of oncological diseases in children is concerned (0.5 versus 0.44). Nevertheless, the prevalence of neuromuscular disorders in children is higher in this study (Pironi's = 4.2 versus 21.2%).

According to Paccagnella *et al.*⁹ literature regarding incidence and prevalence of HEN is insufficient and nearly always refers to works carried out in selected centers. This is also true for Brazil, where no data on HEN incidence and prevalence are available.

In the present study a prevalence of HEN of 81.23 was observed in children. In the work of Pironi *et al.*⁸ a prevalence of HEN of 8.4 was observed in children. Data concerning children are considerably less than in the present work. This may be due to the exclusion of oral supplements in the first work, while in the present one, it corresponded to the main route applied for children.

It is very difficult to compare data on HEN prevalence in children with other findings, since few studies deal with this subject.

The only study involving the use of enteral products through the oral route as a component of the HEN Program

supply was the study of Planas *et al.*⁷ Nevertheless, it is difficult to compare the article mentioned above to the present study, since it involves children, adults and elders.

The oral route in Planas *et al.*⁷ work corresponded to the main route for EN encompassing 54.7% of the cases, lower than in the present study (70.7%), considering the different age groups involved.

As in Daveluy *et al.*¹ and in Diamanti *et al.*⁶, the present study also found a higher frequency of nasal routes (18%) when compared with ostomies, although this study presented the oral one as the main route for HENT.

Daveluy *et al.*¹ state that GT is usually proposed when nutritional support is necessary for longer than two or three months. Some authors indicate even shorter time periods, proposing the use of ostomies whenever nutritional therapy is indicated for periods longer than 4–6 weeks.^{10–12} Despite these recommendations, all studies carried out with children had a higher frequency of nasal routes (excluding oral). The main stated reason for these findings may have been the wide use of EN of short duration for patients, which supports the decision for nasal routes.¹ In DF, however, the highest frequency of nasal routes encountered was for neuromuscular disorders (41%), which usually requires HENT for a longer period of time. In this way, this opposition from the literature recommendations may probably be justified by technical limitations of health-care staff, by lack of professionals trained in ostomy procedures and also by difficulty in fulfilling a great number of percutaneous endoscopic gastrostomy implantations, the reason why at SES/DF the surgical access for ostomies remains higher than percutaneous endoscopic ones.

In spite of the above-mentioned fact, the most frequent indication for GT in the present study were also neuromuscular disorders (43.6%), like Daveluy *et al.*'s findings,¹ which may be indicative of a Brazilian tendency towards technical guidelines.

When it comes to formula prescription, the product most prescribed in the present study was industrial pediatric formula (46.9%), which corresponds to polymeric formulas, followed by hydrolyzed-protein formulas (20.9%) and standard infant formulas (19.2%).

Polymeric pediatric diets were prescribed mainly for EBC (100%), neuromuscular disorders (62.16%) and cystic fibrosis (55.56%). Hydrolyzed-protein formulas were predominantly indicated for patients with malabsorption, such as the findings of Daveluy *et al.*¹ Specialized adult-type diets were administered to children with inflammatory bowel disease (100%), also in consonance with Daveluy *et al.*'s study.¹ Standard infant formulas were mostly prescribed for hepatic metabolic diseases (100%) and congenital cardiopathy (57.14%).

Fiber supplemented enteral preparations accounted for 13% of diets. They were mainly prescribed for EBC (54.2%) and for neuromuscular disorders (29.2%). These findings are very close to those found in Daveluy *et al.*'s study,¹ although they did not deal with EBC patients, as the oral route is the main choice for them. It is important to reinforce that studies assessing tolerance and benefits of fiber-enriched diets for children are urgently needed.¹

It remains essential to emphasize that formula contamination is largely observed in homemade preparations.¹ This justifies the use of industrialized products, especially

for children, as a way to ensure bacteriological security of formulas infused directly in the stomach or intestine.

Unlike the Daveluy *et al.*¹ and Diamanti *et al.*⁶ studies, the first and foremost method of nutrient infusion found in the present work was continuous feeding by gravity. It is worth mentioning that this method of infusion is not very well suited for children, despite its lower costs, because it does not warrant precision of the flow, which may result in gastrointestinal alterations such as diarrhea, abdominal distention, nausea, vomit and others. In spite of these risks, these abnormalities were not reported by patients in the present study.

One limitation of the present study is that no data on patients' complications or hospital readmission was recorded by health professionals. Therefore, a new protocol for data collection was developed (that included details on these data) and will be a subject for further discussion.

Conclusion

This study supports the fact that HEN is necessary in special pediatric conditions, favoring a precocious hospital discharge and then lowering the risk of infectious processes, and stimulating the reinsertion of children in their homes, their safe environment.

This was the first national study to deal with HENT in children and its prevalence, designing the profile of pathologies that lead to HENT, of delivery methods and type of formula prescribed.

It is worth mentioning that in Brazil, the only program concerning HEN supply is the one of the DF. So the need for new studies on national basis addressing HENT efficacy, safety and tolerance in children remains, in order to reinforce the importance of a national legislation that would benefit all Brazilian patients in need of such therapy. These aspects will be a subject for further discussion.

Author contributions: Both authors participated in the design, interpretation of the studies and review of the manuscript; ALRSZ conceived the study, carried out the study and data analyses, performed the statistical analysis and drafted the manuscript; MRCCG contributed to drafting the manuscript. Both authors read and approved the final manuscript.

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Conflict of interest: We certify that there was no involvement in any organization or entity with a direct financial interest in the subject matter or materials discussed in the manuscript. Therefore, there are no conflicts of interest.

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