

Original

Current status of pediatric home enteral nutrition in Spain: The importance of the NEPAD register

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Abstract

Abstract Home enteral nutrition (HEN) is a type of enteral nutrition (EN) which is becoming progressively more widespread in pediatrics due to the benefits it affords to patients, their families and to reducing hospital costs. However, the true extent of its use is unknown in Spain as the data-base set up for this purpose is still underused (Registro de Nutrición Enteral Pediátrica Ambulatoria y Domiciliaria -NEPAD-). More thorough registration of patients in the NEPAD online register will provide information about the characteristics of HEN in Spain: prevalence, diagnosis, the population sector being administered HEN, complications and developments. Likewise, forecast and planning of the necessary resources could be made while those in use could be analysed.

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Introduction

Home enteral nutrition (HEN) is administered outside the hospital. It is apt for patients whose illness is under control but who still require nutritional support. Its ob-

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ESTADO ACTUAL DE LA NUTRICION ENTERAL PEDIATRICA EN ESPANA: LA IMPORTANCIA DEL REGISTRO NEPAD

Resumen

La nutrición enteral domiciliaria (NED) es una modalidad de nutrición enteral (NE) con una progresiva extensión en pediatría por los beneficios que supone para el paciente, sus familiares y la disminución de los costes hospitalarios. Sin embargo, se desconoce su verdadero alcance en España ya que el registro creado a tal efecto está aún infrautilizado (Registro de Nutrición Enteral Pediátrica Ambulatoria y Domiciliaria -NEPAD-). La inclusión exhaustiva de pacientes en NEPAD permitiría conocer las características de la NED en España: prevalencia, indicaciones, población a la que se le está administrando, complicaciones y evolución. Así mismo se podría realizar una previsión y planificación de los recursos que se precisan y analizar los que se están utilizando.

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jectives are to ensure nutritional support in the home and shorten hospital stays thereby reducing treatment costs¹, hospitalism and potential complications of nosocomial infection². It also facilitates reincorporation of patients and their families into school, family, work and social environments and increases survival rate and the quality of life of both children³ and their caregivers⁴.

HEN register

Home enteral nutrition began in the 70s and since then various strategies have been undertaken to widen

its range, reduce costs and improve patient care. However, it is difficult to know the exact impact of HEN, especially in pediatrics, where few cases are reported. There are many reasons: differences in patient follow-up practices depending on the socio-political ambit and the hospital, lack of agreement on the definition of EN and whether or not it encompasses oral feeding, failure to register cases in data-bases, this not being a compulsory requirement⁵. It should be noted that the EN records are essential because they reflect its prevalence, provide information on specific indications, effectiveness and incidence of complications. They are also useful for resource planning and to quantify those in use.

In most countries HEN registers include both pediatric and adult patients, while in Spain there are two separate registers:

1. The National Register of Adults NADYA-SENPE (www.nadia-senpe.com). This is an on-line data-base registering patients since 1992. The latest data from 2007 reveal a prevalence of 113 patients/million inhabitants⁶. This figure is probably lower than the actual prevalence in Spain as it is lower than that recorded in other studies conducted in certain Spanish autonomous regions, in Italy (mean prevalence of 128 patients/million inhabitants/year), in the European register of European Society of Parenteral and Enteral Nutrition (ESPEN HAN <http://www.espen.org>) (163 patients/million inhabitants), the British record kept by the British Artificial Nutrition Survey, 2007 (453 patients/million inhabitants in adults and children, not including oral EN) and United States in the period 1989-1992 (415 patients/million inhabitants).
2. Register of Pediatric Outpatient and Home Enteral Nutrition (NEPAD). This is the online data-base kept by the Spanish Society of Gastroenterology, Hepatology and Pediatric Nutrition (SEGHPN). Launched in 2003, it has been approved by the Ethics Committee of the Hospital Infantil Universitario Niño Jesús in Madrid and the inclusion of patients is optional and meets all the requisites of the Data Protection Act 15/99. Located at <http://www.gastroinf.com/> of SEGHPN, which makes available all additional material for users: informed consent (requesting patient's inclusion in the database), and user's manual. In 2003, NEPAD registered only 124 children from six Spanish hospitals⁷ while in the last assessment undertaken in 2007 (fig. 1 and table I) both the number of patients and hospitals had increased⁸. Although the data are similar to those recorded in other countries, they are probably biased due to the small number of centers they include and the differences among the patients' characteristics. Other pediatric records reflect a higher prevalence, for example the UK BANS records 5250 patients from 253 centers.

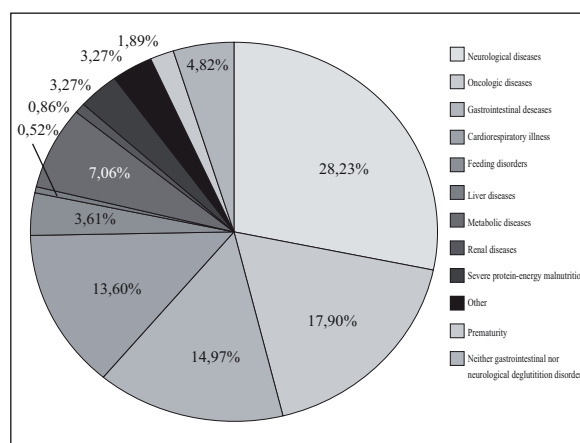


Fig. 1.—Distribution of pediatric HEN by illness.

Table I
Summary of the data gathered in the NEPAD Register 2003-2007

Number of patients	529
Total number of episodes	562
Number of hospitals	13
Male/female (%)	51/49
Average age/ median first indication	3.79 years / 19.3 months
EN tube/oral admin (%)	96.3 / 3.7
Initial admin via tube: NGT / PEG / Jej (%)	64 / 34 / < 2
Changes in initial admin route/ to PEG (%)	10 / 94
Principal mode of delivery: Cyclic/cyclic + bolus (%)	43 / 26
(Total = 69)	
Use of pump (%)	85
NF / NF + formula / formula (%)	5 / 19 / 76
Ppal formula type: full formula (%)	68
Concomitant use of PN (%)	2.7
End of support / recovery of oral feeding (%)	55 / 68.5
Total duration of support /NGT / PEG (months)	8.6 / 2.8/33.9

NGT: nasogastric tube. PEG: gastrostomy. Jej: Jejunal access. Admin.: administration. NF: natural foods. Ppal principal. PN: parenteral nutrition.

Legal framework

Hospital malnutrition and nutritional support are issues of general concern; however, the legal framework and criteria for funding HEN vary from country to country. In Spain, this service has been regulated since 2nd June 1998 by the General Directorate of National Health Service and Inspectorate (*Dirección General de Cohesión del Sistema Nacional de Salud y Alta Inspección*), through the Advisory Committee for dietary product supply. Recently, the legal framework was updated in accordance with the Order *Real Decreto* 1030/2006. Dietary products eligible for financing, registered in the General Health Register of Food as dietary foods for special medical purposes, must be approved by a group of specialists, including pediatricians, in order to be listed as dietary products available (*nomenclator*) by Ministerial Order 3858/2006. In 1998, accompanying the regulation of HEN, guidelines for HEN good clinical practice were issued,

which have recently been updated⁹. Prescription of HEN is usually made by specialists assigned to a hospital nutritional unit, provided the illnesses in question are listed as subject to HEN (Table II).

Psychosocial consequences of HEN

When a child is diagnosed with a chronic illness requiring nutritional support at home, this involves radical changes in family life, often implying extensive use of health resources and changes in family activity¹⁰. Therefore, when establishing HEN one should consider not only the technical aspects but also its impact on the behavioral, psychological and physiological repercussions of the caregivers. Furthermore, the burden of home care generally corresponds to the mother, with likely consequences for her health or social, cultural or professional capacity. A survey conducted in a Spanish hospital revealed the mother is the primary caregiver in most cases and up to 66% claimed to have given up or cut down their occupational activity. Few studies have been made into this impact of HEN on personal, family and social life, nor the potential improvements after its introduction. Currently, these circumstances are not sufficiently covered by health systems and hence the main issues still to be addressed by HEN programs are:

1. The delegation of responsibilities to patients and their caregivers. HEN requires the child's family to be able to take on the responsibility of providing care, receive training and adequate financial support. The Personal Autonomy and Dependent

- Care Law 39/2006 (<http://www.saad.mtas.es/portal/>) is trying to remedy the latter to some extent.
2. The weak link between primary and specialist care.
3. The importance of house-hold associated risks and the detection, management and/or prevention of complications.
4. The extent of use despite the lack of studies on cost-effectiveness.
5. The need for supervision by a multidisciplinary team (Grade A recommendation).

Conclusions

HEN is an increasingly used nutritional support service which enables patients and their families to return to their homes, thereby improving their socialization and "normalization-adaptation" of their way of life. For this to happen, professionals must provide optimal support and monitoring, with a focus on the family, from the moment this support is prescribed. Therefore, there is a need for a multidisciplinary team, which can carry out training and monitoring, making the dispensing of formulas and related equipment both simple and convenient for the patient and providing maximum collaboration with pediatricians in primary care.

Likewise, it is necessary to have a register of this service in order to know about the implementation of HEN in Spain, its use, resources required by our patients and the ability to request them from the corresponding authority. The NEPAD database has this goal; however, it is only useful if we acquire the habit of entering patient information systematically.

Table II
Patients receiving HEN and necessary requisites for financial support by the NHS for treatment with dietary products

Patients receiving HEN

1. Patients with swallowing dysfunction or transit disorders, occurring with severe aphagia and dysphagia and requiring feeding tube*
2. Patients with neuromotor disorders that alter swallowing or transit and require feeding tube
3. Patients with special energy and/or nutritional requirements or in specific clinical instances accompanying severe malnutrition

Necessary and essential requirements for dietary products to be funded by the NHS

- a) The patient's nutritional needs cannot be covered by normal food consumption
- b) The administration of these products can improve the patient's quality of life or afford potential recovery from a life-threatening disorder
- c) Prescription is based on health risk rather than social criteria
- d) The benefits outweigh the risks
- e) Treatment is periodically assessed

*In exceptional cases of severe dysphagia where the feeding tube has counter-indication, EN can be used without feeding tube, with a report to this effect by the clinician responsible for prescribing the treatment.

References

1. Stratton RJ, Elia M; British Artificial Nutrition Survey (BANS). A cost-utility analysis in patients receiving enteral tube feeding at home and in nursing homes. *Proc Nutr Soc* 2008; 67(OCE): E111.
2. Pedrón Giner C, Martínez Costa C. Indicaciones y técnicas de soporte nutricional. *An Esp Pediatr* 2001; 55: 260-6.
3. Loeser C, von Herz U, Küchler T, Rzehak P, Müller MJ. Quality of life and nutritional state in patients on home enteral tube feeding. *Nutrition* 2003; 19: 605-11.
4. Skok A, Harvey D, Reddihough D. Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *J Intellect Dev Disabil* 2006; 31: 53-7.
5. Moreno JM, Shaffer J, Staun M, Hebuterne X, Bozzetti F, Pertkiewicz M et al; Home Artificial Nutrition Working Group-ESPEN. Survey on legislation and funding of home artificial nutrition in different European countries. *Clin Nutr* 2001; 20: 117-23.
6. Cuerda C, Planas M, Gómez Candela C, Luengo L.M and the NADYA-SENPE group. Trends in home enteral nutrition in Spain; analyses of the NADYA registry 1992-2007. *Nutr Hosp* 2009; 24: 347-53.
7. Moreno Villares JM, Pedrón Giner C, Martínez Costa C, Oliveros Leal L, Galera Peinado AP, Rosell Camps A et al. Nutrición enteral domiciliaria en España. Resultados del registro de la Sociedad Española de Gastroenterología, Hepatología y Nutrición Pediátrica del año 2003. *An Pediatr* 2006; 64: 239-43.

8. Martínez Zazo AB, Quijada Fraile P, Pedrón Giner C, Redecillas Ferreiro SE, Moreno Villares JM, Lavilla Oiz A et al. Register of paediatric home enteral nutrition (PHEN) of Spanish Society for Paediatric Gastroenterology, Hepatology and Nutrition from 2003 to 2007. *Clin Nutr* 2008; 3 (Supl 1): 188 (P376).
9. Planas Vilá M, Wanden-Berghe Lozano C, Cuerda Compés MC y Grupo NADYA-SENPE. Guía de nutrición enteral domiciliaria en el Sistema Nacional de Salud. 2ª ed. Madrid: Ministerio de Sanidad y Consumo; 2008. ISBN 978-84-7670-695-4.
10. Nuuzila L, Santaler S. Children with a long-term disease: parents' experience of care. *J Pediatr Nursing* 2006; 21: 153-60.