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A home enteral nutrition (HEN); Spanish registry of NADYA-SENPE group; for the year 2013

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Abstract

Aim: to present the results of the Spanish home enteral nutrition (HEN) registry of the NADYA-SENPE group for the year 2013.

Material and methods: from January 1st to December 31st 2013 data was recorded for the HEN registry and further descriptive and analytical analysis was done.

Results: in this period 3223 patients (50.6% men) and a total of 3272 episodes of HEN were registered in 33 Spanish hospitals. The rate of prevalence was of 67,11 patients/million habitants/ year 2013. A high percentage of patients (98,24%) were older than 14 years. Adult's mean age was 69,14 years (sd 17,64) and men were younger than women p-value <0,001. Children mean age was 2,38 years (sd 4,35). The most frequent indication for HEN was neurological disease for children (49,1%).

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REGISTRO DEL GRUPO NADYA-SENPE DE NUTRICIÓN ENTERAL DOMICILIARIA EN ESPAÑA; AÑO 2013

Resumen

Objetivo: exponer los resultados del registro de nutrición enteral domiciliaria (NED) del año 2013 del Grupo NADYA-SENPE.

Material y métodos: se recopilaron los pacientes introducidos en el registro desde el 1 de enero al 31 de diciembre de 2013, procediendo al análisis descriptivo y analítico de los datos.

Resultados: durante este periodo se registraron 3.223 pacientes, (50,6% varones) y un total de 3.272 episodios de NED en 33 hospitales españoles. La tasa de prevalencia fue de 67,11pacientes/millón de habitantes/año 2013. El 98,24% de los enfermos tenía más de 14 años. La media de edad de los adultos fue de 69,14 años (dt 17,64) y la mediana se situó en 73 años (IIQ 58-83), siendo los varones más jóvenes que las mujeres; p-valor < 0,001. Los niños tuvieron una edad media de 2,38 años (dt 4,35). La enfermedad que con más frecuencia motivó el uso de la NED fue la patología neurológica en niños (49,1%) y en adultos (60,6%). La vía de administración más utilizada en los niños fue la gastrostomía (51%), siendo los niños más

and for adults (60,6%). Gastrostomy was the most used administration route for children (51%) while younger ones were fed with NGT (p-value 0,003) also older adults (48%) were fed with this type of tube (p-value <0,001). The most frequent reasons for cessation of treatment was death, 44,4% were children and 54,7% were adults.

Conclusions: **The number of patients and hospitals registered increased in the last years while the other variables maintain steady. The registry developed allowing contrasted analysis of data in order to get more information.**

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pequeños los que se alimentaban por SNG (p-valor 0,003) y en los adultos (48%), siendo estos pacientes los de mayor edad (p-valor <0,001). El motivo más frecuente de finalización del tratamiento fue la muerte del paciente; 44,4% en niños y 54,72 en adultos.

Conclusiones: **el número de pacientes y de hospitales registrados aumentan en relación con los años anteriores, mientras que las demás variables mantienen un equilibrio estacionario. El registro ha evolucionado, permitiendo un análisis contrastado de los datos, lo que nos ofrece mayor información.**

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Palabras clave: *Nutrición enteral. Soporte nutricional. Cuidados domiciliarios. Registros.*

Introduction

The home enteral nutrition (HEN) is the therapeutic method to restore or maintain nutritional status, by the administration at home of the necessary nutrients via the digestive tract in patients who can´t have a regular consume of food due to their clinical situation.

This modality of artificial feeding of patients at home responds to the need to reintegrate patients back to their usual environment avoiding long periods of hospitalization, allowing familiar conciliation and improving the perceived quality of life of family and patient[1]. In turn, it allows the availability of empty beds, which reduce the hospitalization and healthcare costs related to the complications proper of a long hospitalization period[2,3].

The home and ambulatory artificial nutrition group of the Spanish Society of Enteral and Parenteral Nutrition (NADYA-SENPE) has since 1992 a registry that collects the characteristics of the HEN and periodically communicates their results[1,5-11]. From its beginning the collected information included the oral via but from the year 2011 only the information related to the nutrition administrated by any type of tube was taken, not including patients whom are fed though oral via even though they are having defined artificial formulas.

The aim of this work is to communicate NADYA group registry results for the year 2013.

Material and Methods

From January 1st to December 31st 2013 data was recorded for the HEN registry of NADYA-SENPE group (www.nadya-senpe.com) for patients who had enteral tube feeding. The date of query was 01-03-2015. For data processing adults and pediatric patients aged 14 years or less were considered. For prevalence rate calculation the data registered of the study population by the National Statistic Institute (INE) (http: // www.ine.es) for the year 2013 was used.

Descriptive techniques were applied for absolute frequency calculation and the related to the qualitative variables and in the case of the quantitative variables means and their standard deviation (SD) (or medians and interquartile range- IQR-, depending on distribution) were used. This was done in order to clarify about the exiting distribution.

For the analysis between variables chi-square, t-student and ANOVA test were used. The most relevant outcomes are detailed in the tables and figures. Quality control was done using cross-table data, when errors were found the original sources of the data were consulted. For data analysis Statistical Package for the Social Sciences SPSS® 22.0 was used.

Results

In this study 3.223 patients and a total of 3.272 episodes of HEN were registered (Fig. 1). Patients were from 33 Spanish hospitals with a mean of 94 patients for each hospital, a great variability was seen (max. 509-min. 2). The rate of prevalence was of 67,11 patients/million habitants/ year 2013, 50,6% of them were men.

Children: A total of 55 were registered, they represented 1,76% of the study sample. They belonged to 14 Spanish hospitals (max. 20-min1) with a total of 56 episodes due to one child had 2 episodes of HEN. Girls represented 54,5% of the sample. The mean age was 2.38 years (SD 4.35) and the median was placed in 0 years (IQR 0-2) significant differences were not found for the mean age between girls and boys, p-value 0,692. The indication for HEN was neurological disease with aphagia or severe dysphagia in 49,1% of the patients (Fig. 2). The principal via of administration was gastrostomy in 51% of them and the nasogastric tube (NGT) in 47,6%, the younger ones were preferably fed by the NGT p-value 0,003. Median time of nutritional support was of 706 days (IQR 539-900). Nine episodes of HEN were finalized due to death in 44,4% of them, a 33% returned to oral via while in

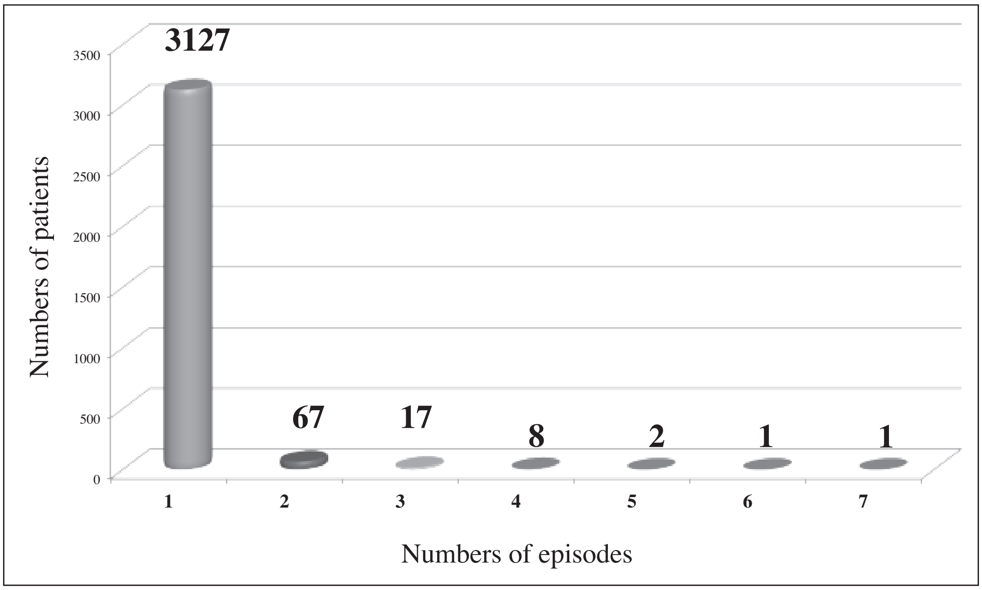

Fig. 1.—Home Enteral Nutrition episodes recorded during 2013.

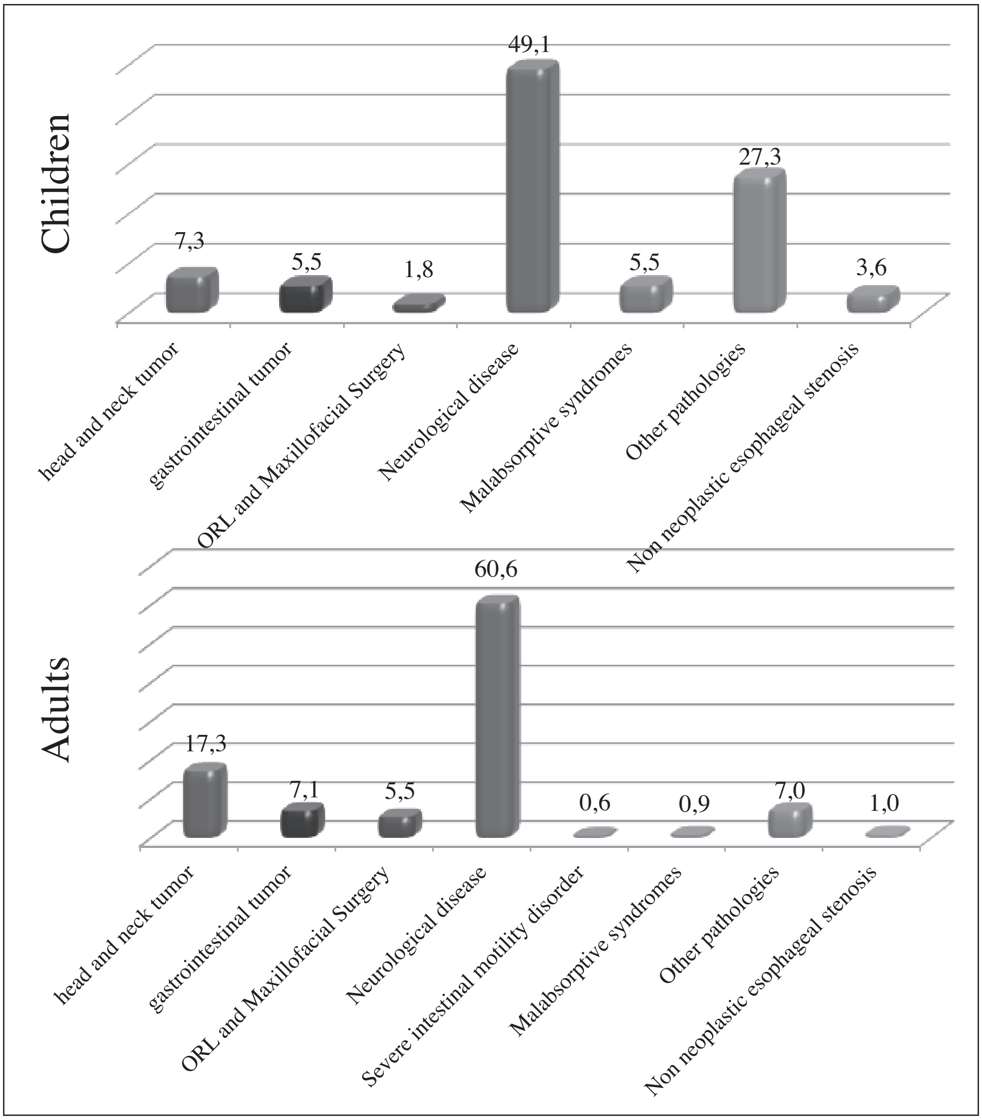

Fig. 1.—Home Enteral Nutrition episodes recorded during 2013.

22,2% presented other reasons. No relation was found between age and finalized reasons with a p-value of 0,422. Formulas needs were supplied in 63,3% by pharmacy and for 27,3% by hospitals, primary care for 3,6% of cases and commercial company in 1,8%. Consumables were provided in 78.2% of cases by the hospital, 16.4% by the primary care service and 5.5 listed as 'not required'.

Adults: A total of 3168 adults were registered and represented 98.24% of study simple. Belonged for 32 Spanish hospitals (max 507-min 1) and presented a total of 3216 episodes of HEN. Men were 50,7% of the sample. The mean age was 69,14 years (SD 17,64) and median placed in 73 years (IQR 58-83) men were younger then women with a p-value<0,001. The most frequent diagnosis that ned the use of HEN was neurological disease with aphagia or severe dysphagia in 60,6% of the cases (Fig. 2). The principal via of administration was NGT in 48,0% followed by gastrostomy in 40,8% of the cases with a higher mean age for NGT patients compared with patients who had another administration via p-value<0,001 and patients with jejunostomy were the youngest ones p-value<0,001. The median time of nutritional support was 589 days (IQR 206-950). Death was the reason for the finalization of 943 episodes of HEN (29,32%), in 17,1% because they could be fed by oral via, other 0,32% passed to parenteral nutrition and in 27,86% was for another reasons. The mean age of those who passed to oral via was lower than deceased patients p-value 0,001 and than patients that finalized for another reasons p-value<0,001. Physical activity in 49,4% of patients was reduced to bed-couch and required total assistance in 56,5% of them (Fig. 3). Nutritional formulas needs were supplied in 67,2% by pharmacy and in 25,7% of the cases by hospital. Consumables were given in 57,0% of cases by hospital, for 29% by the primary care services and the rest of patients listed as not required'.

Discussion

From the beginning of NADYA registry, the number of episodes of home enteral nutrition is constantly increasing year after year, while we can observe in the literature that 2010 was the last year were enteral nutrition was registered by oral via[10] this fact must be considered if the aim to show the evolution in these last years of the number of patients and/or episodes to avoid wrong conclusions.

Also a higher number of participating centers with registered patients were observed but this was not seen for all the centers of our group. This is one of the disadvantages of the voluntary registries[12]; its compliance must be simultaneous with the daily work of healthcare that each day has to be responding.

For years the concern of the NADYA group through its registry is to offer the maximum information about artificial nutrition in Spanish and ensure that this information allows us to learn about the characteristics of the patients although we are aware that not all patients with HEN are collected. In this sense, we can interpret that during this years patients that had this type of treatment have majorly neurological diseases and that the elder adults have the tendency to be fed by NGT while the youngest adults will be fed by a GEP tube.

The duration of the episodes has increased; a total of 351 days were seen for the years 2011 and 2012 this can explain that despite the chronicity of the patient if is properly fed in his home this can increase his life expectancy. But we must contemplate the possibility of a small bias related to the updated of patients in the registry.

The available data about children could probably be under-represented as in the case of the adults because there wasn't a total and exhaustive participation of the centers with HEN patients. In addition, due to the existence of a specific registry of pediatric patients with ambulatory and home enteral nutrition (NEPAID)[13].

We consider that NADYA-SENPE registry is still very useful to estimate the overall and community trend of EN prescription and the characteristics of patients that receive healthcare from the National Health System. Without forbidding that some limitations have yet not been solved, as the registry is voluntary, the data must be simple to facilitate its collection and make possible increase the participation. Also is desirable that related complications could be registered

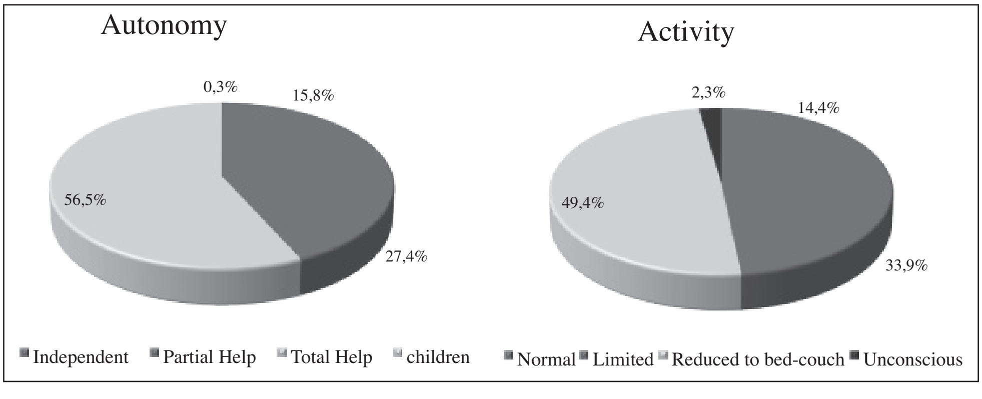

Fig. 3.—Level of autonomy and activity of patients with Home Enteral Nutrition.

and the data related to the evolution of patients could be updated in real time, avoiding potential loss of follow-up. In the last years progress has been made improving the quality of entered data by incorporation an outlier data search protocol and it has been possible to get data that allows us do hypothesis contrast. It could be interesting to incorporate as a result measure a quality of life questionnaire of these patients[14]. We hope to continue on improving the structure of the registry and increasing for each year the number of participating centers.

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