Hospitalaria

Original/*Nutrición parenteral*

A home and ambulatory artificial nutrition (NADYA) Group Report, Home Parenteral Nutrition in Spain, 2013

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Abstract

Aim: **to communicate the results of the Spanish Home Parenteral Nutrition (HPN) registry of the NADYA-SENPE group for the year 2013.**

Material and methods: **data was recorded online by NADYA group collaborators that were responsible of the HPN follow-up from 1st January to 31st December 2013.**

Results: **a total of 197 patients and 202 episodes of HPN were registered from 35 hospitals that represents a rate of 4,22 patients/million habitants/year 2013. The median age was 53 years (IQR 40 – 64) for 189 adult patients and 7 months (IQR 6 – 35,5) for children. The most frequent disease in adults was neoplasm (30,7%) followed by other diseases (20,1%) and mesenteric ischemia (12,7%). Short bowel syndrome and intestinal obstruction (25,9%) were in 35.7% cases the indications for HPN.**

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NUTRICIÓN PARENTERAL DOMICILIARIA EN ESPAÑA DURANTE 2013, INFORME DEL GRUPO DE NUTRICIÓN ARTIFICIAL DOMICILIARIA Y AMBULATORIA NADYA

Resumen

Objetivo: **comunicar los datos del registro de Nutrición Parenteral Domiciliaria (NPD) del grupo de trabajo NADYA-SENPE del años 2013.**

Material y métodos: **recopilación de los datos del registro "on-line" introducidos por los colaboradores del grupo NADYA responsables del seguimiento de la NPD desde el 1 de enero de 2013 al 31 de diciembre de 2013.**

Resultados: **se registraron 197 pacientes, procedentes de 35 hospitales, lo que representa una tasa de 4,22 pacientes/millón habitantes/año 2013, con 202 episodios de NPD. La edad media de los 189 pacientes mayores de 14 años fue de 53 años (IIQ 40 – 64), y en los niños de 7 meses (IIQ 6 – 35,5). La patología más frecuente en los adultos fue la neoplasia (30,7%) seguida por otras patologías (20,1%) y la isquemia mesentérica (12,7%). En el 35,4% de los casos el motivo de indicación fue el síndrome de intestino corto, seguido de la obstrucción intestinal (25,9%).**

En los niños el diagnóstico más frecuente fueron las alteraciones congénitas intestinales y 'otros diagnósticos',

The most frequent diagnosis for children were the congenital intestinal disorders and other diagnosis, both with a (37,5%) and short bowel syndrome and intestinal obstruction were the indication for treatment, each was present in 50% of the sample.

Tunneled catheters (50%) and subcutaneous reservoirs (27,7%) were frequently used. The septic complications related with catheter were commonly frequent with a rate of 0.74 infections/1000 HPN days.

HPN duration presented a median of 1,69 days. A total of 86 episodes finalized during the year, death was the principal reason (45%), followed by "resumed oral via" (43,75%) while it happened inversely for children, 66,7% of them resumed oral via and 16,7% deceased. Fifteen per cent were considered for intestinal transplant, children were proportionally candidates, p-value 0.002.

***Conclusions:* the number of participating centers and registered patients increased progressively respect to preceding years. Since 2003 Neoplasm is still being the principal pathological group. Death is adult's principal reason for finalizing HPN and "resuming oral via" for children. Despite that NADYA registry is consolidate as a essential source of relevant information about the advances in Home Artificial Nutrition in our country, currently is in an improvement process of the available information about patients characteristics with a special emphasis on children even though they still being a minority group.**

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ambas con un 37,5 %, y la causa de la indicación el síndrome de intestino corto y la obstrucción intestinal, que se repartieron el 50% de la muestra.

Los catéteres más utilizados fueron los tunelizados (50%) y los reservorios subcutáneos (27,7%). Las complicaciones más frecuentes fueron las sépticas, relacionadas con el catéter, con una tasa de 0,74 infecciones/1.000 días de NPD.

La duración de la NPD presentó una mediana de 1,69 años. Durante el año finalizaron 86 episodios, la principal causa de la finalización en adultos fue el fallecimiento (45%) seguido del 'paso a la vía oral' (43,75%) y en los niños a la inversa 66,7% pasan a vía oral y 16,7% fallecen. Se consideraron candidatos para trasplante intestinal el 15% de los pacientes, siendo proporcionalmente los candidatos niños, p-valor 0,002.

***Conclusiones:* se observa un aumento progresivo de los centros participantes y de los pacientes registrados respecto a años anteriores. El principal grupo patológico sigue siendo oncológico, ocupando el primer lugar desde 2003. La principal causa de finalización de la NPD es en los adultos el fallecimiento y en los niños el 'paso a vía oral'. Aunque el registro NADYA es un registro consolidado y ha sido y es fuente imprescindible de información relevante para el conocimiento de los avances de la Nutrición Artificial Domiciliaria en nuestro país, se encuentra en proceso de mejorar la información que ofrece sobre las características de los pacientes, con especial atención en el grupo de niños, aunque estos siguen siendo un número reducido.**

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Palabras clave: *Nutrición Parenteral Domiciliaria. Nutrición Parenteral. Soporte nutricional. Cuidados domiciliarios. Registros. Epidemiología.*

Introduction

Home Parenteral Nutrition (HPN) consists in the administration of parenteral nutrition solutions in patient's environment[1]. By this way it ensures that patients need feeding by parenteral via because otherwise couldn't survive, can choose freely their home as place of treatment. In occasions patient's functional status allows to get integrated socially and to return to job or study again.

At the end of 1960s the first news about this type of nutritional care were in United States of America. The first hospital discharge of HPN in patient happened in December[2] of 1969 further were other events as Jeejeebhoy et al experience in 1973 that published "Total parenteral nutrition at home for 23 months, without complication, and with good rehabilitation. A study of technical and metabolic features"[3]. They instantly noticed[3] that to achieve this objective; ensuring a safe way of patient's home nourishment, increasing his quality of life with a better conformability and higher survival expectancies, it was necessary to have a multidisciplinary team able to perform each stage of a complex program that includes; patients selection plus the caregiver and patient's training in the solution's administration and catheter care[4].

Since 1992 the group of Home and Ambulatory Artificial Nutrition (NADYA) of Spanish Society of Enteral and Parenteral Nutrition[5] (NADYA-SENPE) develops educational and training material addressed for professionals, patients and their relatives as manuals, clinical guides, training videos to collaborate in HPN quality and safeness. Thus in order to recognize the real situation of this type of treatment and patient's characteristic in the Spanish context. NADYA registry stays up to date and realizes annual reports for this treatments[6-10].

Material and Methods

A descriptive analysis was performed of collected data for NADYA-SENPE group registry (www.nadyasenpe.com). Registered data of patients with HPN from 1rst January to 31st December of 2013 was the criteria for this work.

For data processing adults and pediatric patients aged 14 years or less were considered. Descriptive techniques were applied for calculation of absolute and relative (percentage) frequencies of variables and in the case of the quantitative variables means or medians and its standard deviation (SD) or interquartile range

(IQR) were used depending on variable distribution. The most relevant outcomes were detailed in tables and figures. When it was possible the analysis between variables, chi-square, t-student and ANOVA test were used. The annual population mean for the year 2013 available at the National Statistic Institute Website (INE) (http: // www.ine.es) was used as denominator for prevalence rate calculation. 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

A total of 197 patients from 35 hospitals were registered, the geographic distribution of patients and their correspondent centers is shown in figure 1. A great variability was found for patients distribution with a mean of 5,5 for each hospital (min. 1 y max. 17) and a mode of 1 patient. The rate of prevalence was of 4,22 patients/million habitants/ year 2013, with 202 episodes of HPN.

The median age between 189 (95,9%) of the adults (> 14 years) was 53 years (IIQ 40 – 64), the youngest patient was 16 years and the oldest was 84 years. Women were 53,3% of them. The most frequent disease present in adults (Fig. 2) was neoplasm (30,7%) followed by another pathologies (20,1%) and mesenteric ischemia (12,7%). Short bowel syndrome (35,4%) and intestinal obstruction (25,9%) were the indications for HPN (Fig. 3). Tunneled catheters (49,1%) and subcutaneous reservoirs (28,8%) were frequently used. HPN duration presented a median of 613 days IQR 132 – 1412 (1,68 years; IQR 0,4 – 3,8). HPN was the only nutritional support in 49,7% of the patients, oral food intake was present in 40,2% of total patients while HPN was supplemented with enteral nutrition in 10,1%. A total of 80 episodes were finalized during the year (Fig. 4), death was the principal reason in 45% and resuming to oral via was in 43,7%. The main supplier of paternteral nutrition bags was the reference hospital in 70,6% followed by catering company in 23,7%. Also consumables were administrated by the hospital in 87,3% and from primary healthcare services for 20,6% of the patients.

Eight (4,1%) children were registered which represented a prevalence rate of 1,13 children/million habitation ≤ 14 years/year 2013. Fifty per cent of them were girls and the median age of all children was 7 months (IQR 6– 35,5). The most frequent diagnosis (Fig. 2) were "intestinal congenital disorders" and "other diagnosis", both of them represented a frequency of 37,5% and the main reason for HPN indication was "Short bowel syndrome" and "intestinal obstruction", each was present in 50% of the sample (Fig. 3). Tunneled catheters (71,4%) and peripherally inserted

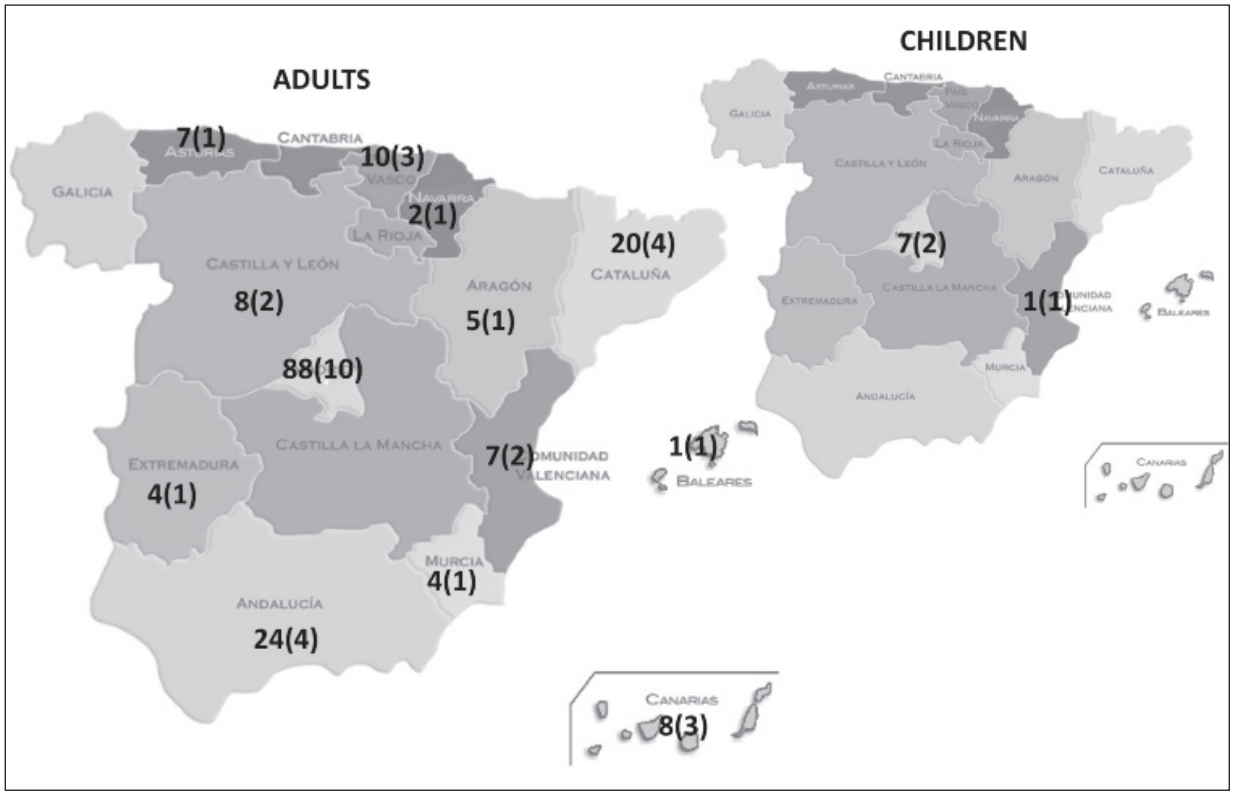

Fig. 1.— Number of participating patients and centers in NADYA registry for 2013 in each Autonomous Community.

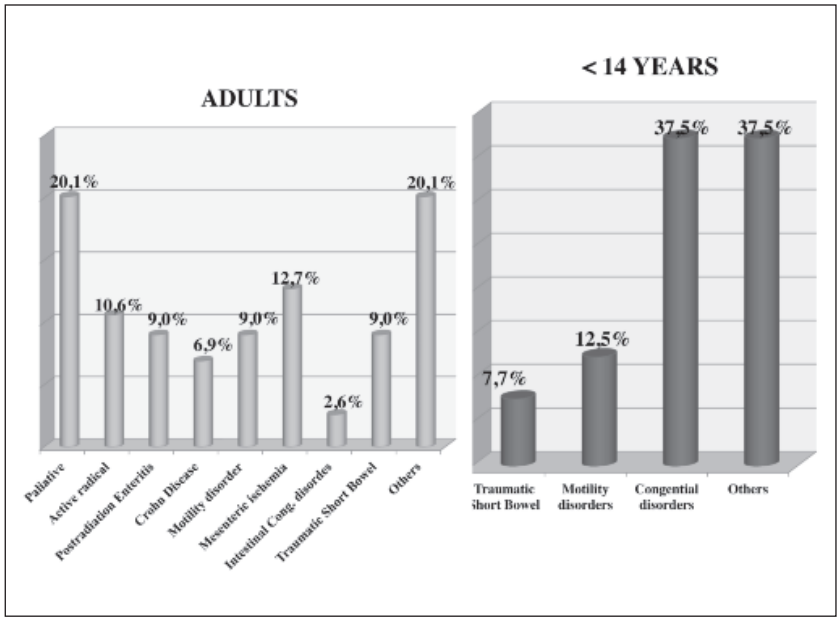

Fig. 2.— Diagnosis of patients with HPN during the year 2013.

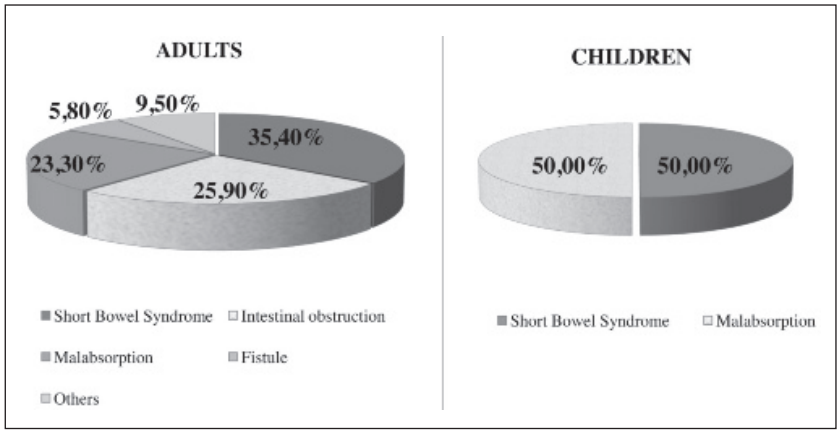

Fig. 3.— HPN indication for patients of NADYA registry 2013.

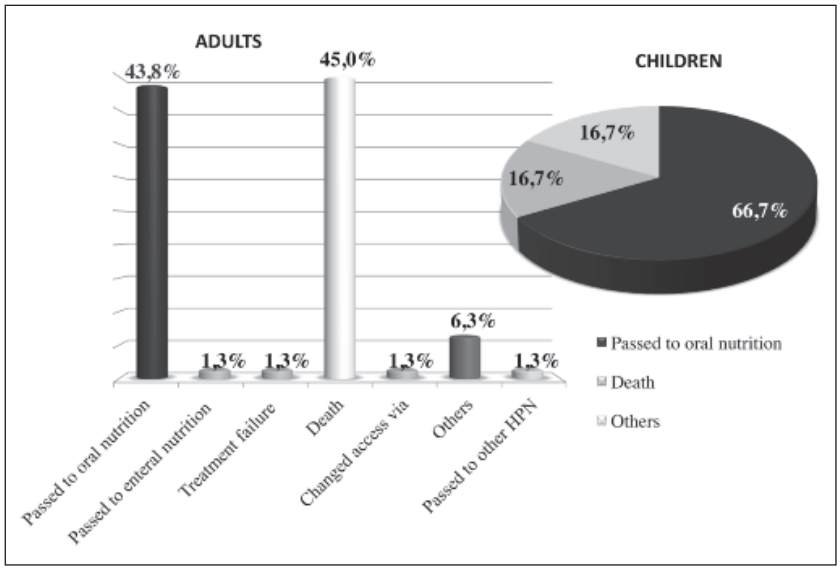

Fig. 4.— Reasons of HPN episodes finalization during the year 2013.

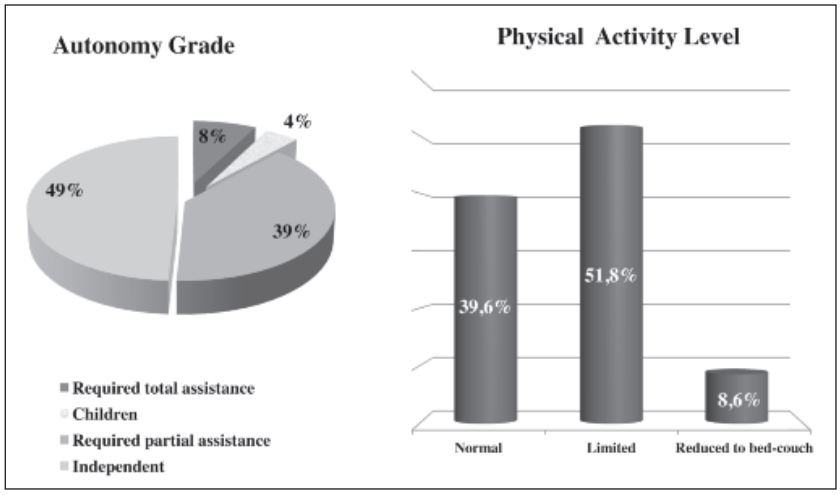

Fig. 5.— Physical activity level and autonomy grade of HPN patients during 2013.

central catheters (28,6%) were commonly used. The duration of HPN had a median of 2.025 days IQR 186 – 4.327 (5,55 years; IQR 0,5 – 11,8). It consisted in the unique nutritional support in 25% of episodes, 75% of the total kept oral intake. During the year, 6 (75%) episodes finalized, the main reason was resuming to oral via in 66,7% (Fig. 4). The common supplier of parenteral nutrition formula was the catering company (62,2%) followed by the reference hospital (37,5%), but consumables for HPN administration were supplied in 100% by the reference hospital.

In all the registries the reason of finalization was related to the diagnosis group, resuming to oral via was presented in higher proportion in intestinal disease group compared to neoplasm group, p-value 0.002. Sepsis related to catheter was the most frequent complication with a rate of 0,47 infections/1000 days of HPN, no differences were found between children and adults (p-value 0,590); followed by metabolic type 0,27/1000 days (p-value 0,106) and others related to catheter with 0,21/1000 days (p-value 0,436).

Fifteen per cent of the patients were candidates for intestinal transplantation; children were proportionally candidates, p-value 0,002.

Physical activity was limited in 51,8% of patients and it was normal and self-dependent in 49,2% (Fig. 5).

Discussion

A progressive increase is observed as in previous reports of this type of treatments supplied at home but with a special emphasis for the higher number of participant centers, (19 in 2006; 21 in 2007; 24 in 2008 and 2009; 23 in 2010) which increase also progressively[1,5,6].

There is still exiting two principal diagnosis groups for the HPN patients, the neoplasm and gastrointestinal patients. The administration of HPN is increasing in cancer patients, it seems to be a tendency but there is no avaiblale updated data from previous registries to make a comparison of it. Even for terminal cancer patients with intestinal obstruction receiving palliative treatment at home[9].

For this year the registration of the venous type access has increased considerably in 84,3% (52,9% of the total patients in 2007; 32,7% in 2009; 83,2% in 2012)[6,7]. Tunneled catheter is still being the most frequently used, even though it decsreased from a 62% in 2011 to 49,1% for this year, it happened at the expense of a considerable increase of subcutaneous reservoirs[6]. The use of this type of catheters could be explained by the prevalence of cancer patients in this registry, because they already have this route of vascular access used for chemotherapeutic treatment before beginning the HPN.

The number of reported complications is still being lower than those recorded in the same context (Spanish Territory) in series published by any of the centers at an individual level, lately Higuera et al 2014, published a retrospective revision of their HPN patients from 1986, founding a rate of 3,58 infections/1000 days of HPN[10]. No significant differences were found between children and adults complications.

Although death is still being the most frequent reason for HPN episodes finalization[6-8], an equal tendency of "resumed oral via" was observed and of which are primarily responsible the episodes in patients with gastrointestinal diseases.

Children are considered candidates for intestinal transplant in a higher proportion. Despite the fact that the number of children had been maintained stable in the last years (between 8 and 10 since 2006) it decreased to 15% of the total of registered patients, this data is still stable respect to the year 2012 in which they were 14,8% candidates, being this the first year that the number decreased abruptly after being maintained steady with a range between 23% and 29%; (27% in 2006; 26% in 2007; 29% in 2008; 23% in 2009; 24,68% in 2010 y 24,68% in 2012)[1,6-8,13].

The hospital is still being the principal supplier of parenteral nutrition bags as well as consumables for

its administration, but it is observed that the catering company is in main supplier for children, this fact changed because previously the hospital assumed all pediatric patients[13], now two thirds of the children receive the bags at home prepared "à la carte" as prescribed by the attending physician and elaborated by a specialized company.

NADYA registry seeks to offer every year a deep and exhaustive analysis of the most relevant characteristics of home artificial nutrition in Spain. Obviously, continues on having important limitations. The most important one is being a voluntary registry which essentially depends on the scientific munificence of its participants, generally are healthcare professionals with overloaded assistance care that dedicate time to collaborate with NADYA. This makes our team assume that for some variables there could be "bias information" even though of the quality control that the data is subjected such as the number of registered complications that depends on the awareness of participants about its importance for having more reliable data. Another limitation is the small number of registered children, in comparison to the prevalence recorded in Juana-Roa[11] study that found 27 children with a prevalence rate of 4,01 children/ million habitants ≤ 14 years / year 2008 by surveying the pharmacy services of 713 Spanish hospitals.

A future goal that could be appropriate for NADYA registry is to registered evolutionary clinical parameters of patients[12].

We appreciate the collaboration of all NADYA-SENPE group members for their disinterested dedication to keep on active the registry of home artificial nutrition patients.

We would like to invite all the professionals that monitors patients with enteral or home parenteral nutrition to include them in this registry in order to learn more with the highest reliability and quality about the reality of patients with home artificial nutrition in our country.

We also want to acknowledge and thank the support of Braun SA in the maintenance of the registry.

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