



Original / *Nutrición enteral*

## Home enteral nutrition in Spain; NADYA registry 2011-2012

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### Abstract

**Objective:** To describe the results of the home enteral nutrition (HEN) registry of the NADYA-SENPE group in 2011 and 2012.

**Material and methods:** We retrieved the data of the patients recorded from January 1<sup>st</sup> 2011 to December 31<sup>st</sup> 2012.

**Results:** There were 3021 patients in the registry during the period from 29 hospitals, which gives 65.39 per million inhabitants. 97.95% were adults, 51.4% male. Mean age was 67.64 ± 19.1, median age was 72 years for adults and 7 months for children. Median duration with HEN was 351 days and for 97.5% was their first event with HEN. Most patients had HEN because of neurological disease (57.8%). Access route was nasogastric tube for 43.5% and gastrostomy for 33.5%. Most patients had limited activity level and, concerning autonomy, 54.8% needed total help. Nutritional formula was supplied from chemist's office to 73.8% of patients and disposables, when necessary, was supplied from hospitals to 53.8% of patients. HEN was finished for 1,031 patients (34.1%) during the period of study, 56.6% due to decease and 22.2% due to recovery of oral intake.

**Conclusions:** Data from NADYA-SENPE registry must be explained cautiously because it is a non-compulsory registry. In spite of the change in the methodology of the registry in 2010, tendencies regarding HEN have been maintained, other than oral route.

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### NUTRICIÓN ENTERAL DOMICILIARIA EN ESPAÑA; REGISTRO NADYA DEL AÑO 2011-12

### Resumen

**Objetivos:** Describir los resultados del registro de nutrición enteral domiciliaria (NED) del grupo NADYA-SENPE de los años 2011 y 12.

**Material y métodos:** Se recopilaron los datos introducidos en el registro desde el 1 de enero de 2011 al 31 de diciembre de 2012.

**Resultados:** Hubo 3021 pacientes en el registro durante el periodo, procedentes de 29 hospitales, lo que da una prevalencia de 65,39 casos por millón de habitantes. 97,95% fueron adultos, 51,4% varones. La edad media fue 67,64 ± 19,1 años y la mediana 72 años para los adultos y 7 meses para los niños. La duración media de la NED fue 351 días y para el 97,5% fue el primer episodio con NED. La mayoría de pacientes tenían NED por una enfermedad neurológica (57,8%). La vía de acceso fue sonda nasogástrica para el 43,5% y gastrostomía para el 33,5%. La mayoría de pacientes tuvieron un nivel de actividad física limitado y, respecto a la autonomía, 54,8% necesitaba ayuda total. La fórmula de nutrición se suministró desde las oficinas de farmacia para el 73,8% y los fungibles, cuando fueron necesarios, desde los hospitales para el 53,8%. La NED se suspendió en 1.031 pacientes (34,1%) durante el periodo de estudio, 56,6% debido a fallecimiento y 22,2% debido a recuperación de la vía oral.

**Conclusiones:** Los datos del registro NADYA-SENPE deben ser interpretados con precaución ya que se trata de un registro voluntario. A pesar del cambio de metodología del registro en 2010, las tendencias en NED se han mantenido, salvo la importancia cuantitativa de la vía oral.

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Palabras clave: *Nutrición enteral. Cuidados ambulatorios. Registros.*

## Introduction

Home enteral nutrition (HEN) deals with the provision of enteral formulas in the digestive tract of patients in their own home. Usually, it is done through tubes which lead those formulas to the indicated level: stomach, beyond pylorus or in jejunum. Nasogastric tubes are the most frequently employed<sup>1,2</sup>.

This type of nutritional treatment, by being done outside hospitals, results in an improvement on independence, autonomy and quality of life of patients and their caregivers<sup>3</sup>, as well as savings for the health system<sup>4,5</sup>.

Home and outpatients artificial nutrition group (*grupo de Nutrición Artificial Domiciliaria y Ambulatoria*) of Spanish Parenteral and Enteral Nutrition Society (NADYA-SENPE) does a national registry of the patients treated with HEN in Spain since 1992<sup>6</sup>. Since then, it has contributed to the development of clinical guidelines<sup>7</sup>, handbooks and educational media directed to patients, which may be accessed through the webpage of the group<sup>8</sup>. NADYA also publishes periodical reports of the registry in scientific literature of this area<sup>1,9-20</sup>, showing an increase in the prescription of HEN in the last years<sup>21,22</sup>.

The aim of this report is to describe HEN data registered by NADYA group during the years 2011 and 2012.

## Material and methods

We performed a descriptive analysis of the data collected by NADYA-SENPE group ([www.nadya-](http://www.nadya-)

[senpe.com](http://www.nadya-senpe.com)) in HEN Spanish national registry of the years 2011 and 2012 (data base consulted on December 5<sup>th</sup>, 2013). Consultation criteria were all the patients with HEN registered by every Spanish collaborative centre since January 1<sup>st</sup>, 2011 to December 31<sup>st</sup>, 2012.

We considered as paediatric population, regarding the treatment of data, patients aged 14 or younger, and adults the rest of the patients.

In order to calculate frequencies per inhabitant, we used the data registered by *Instituto Nacional de Estadística* (INE) by January 1<sup>st</sup>, 2012 (<http://www.ine.es>).

We used descriptive techniques by the calculation of absolute and relative frequencies of qualitative variables, and, in the case of quantitative ones, we employed media and standard deviation (SD) (or median and interquartile range (IR), depending of the distribution). The most relevant values are presented further in tables and figures. Information quality control was developed through double-data entry tables. Mistakes discovered were corrected by the consultation with the original registry.

For the analysis of data we used statistical program SPSS® 21.0.

## Results

During the period 2011-2012, 3021 patients from 29 Spanish hospitals were recorded in the registry (fig. 1), what gives a frequency of 65.39 patients with HEN/1 million inhabitants, 51.4% of them were male and



Fig. 1.—Geographical distribution of hospitals (n).

2.05% (62 patients) were paediatric patients (children); mean  $\pm$  SD age was  $67.64 \pm 19.1$ , median age was 72 and IR 57-83; median age of children was 7 months, IR 0.75-22.75 months.

For most patients this was their first time with HEN (2944 patients, 97.5%), although we found 59 patients (2.0%) in their second period, 14 (0.5%) in the third, 3 (0.1%) in the fourth and a single patient in the fifth.

Median duration with HEN was 351 days (IR 158-672), without any differences between adults and children ( $p = 0.76$ ).

The most common diagnosis was “Neurological disease which causes aphagia or severe dysphagia” (1709, 57.8% among adults; 29, 46.8% among children) (fig. 2). Access routes employed in children were nasogastric tubes (27, 43.5%), gastrostomy (21, 33.9%) and only 1 jejunostomy (1.6%), although in 13 patients access route were not recorded. Among adults, the most common route in the first period with HEN was nasogastric tube (1343, 45.3%), followed by gastrostomy (871, 29.4%), although in the consecutive periods with HEN we found that the most common access route was gastrostomy. In fact, 47 patients in their second period with HEN had gastrostomy (63.5%) and 27 had nasogastric tube (36.48%); 13 patients in their third period, had gastrostomy (72.2%) while 5 had nasogastric tube (27.7%); nasogastric tube disappear in the consecutive periods with HEN.

All the complications were registered among adults, and most of them happened during the first period with HEN (fig. 3). Infectious complications related with access route were the most common, with 43 events, followed by loss of the tube in 36 events.

Most of the patients had a limited activity level: chair to bed life 1521 patients, 50.3%; limited 1009, 33.4%; normal 514, 17.0%; unconscious 77, 2.5%. Regarding autonomy, 1690 patients (54.8%) needed help totally; 813 (26.4%) needed help partially; and 582 (18.9%) were independent.

Nutrition formula was provided from hospital to 684 patients (21.9%), from chemist’s office to 2303 patients (73.8%), and directly from the commercial nutrition company to 134 patients’ homes (4.3%). Disposables were provided by hospitals to 1681 patients (53.8%), from Primary Care to 954 patients (30.6%), from other origins to 179 patients (5.7%), and 307 patients did not precise disposables (9.8%).

1,031 patients (34.1%) finished HEN in the period of study, 17 of them were children (27.4%). The most common cause was decease (584 patients, 56.6%; 10 children, 58.8%), followed by recovery of oral intake (229 patients, 22.2%; 5 children, 29.4%).

## Discussion

There are few registries of artificial nutritional support in the literature, most of them provided by

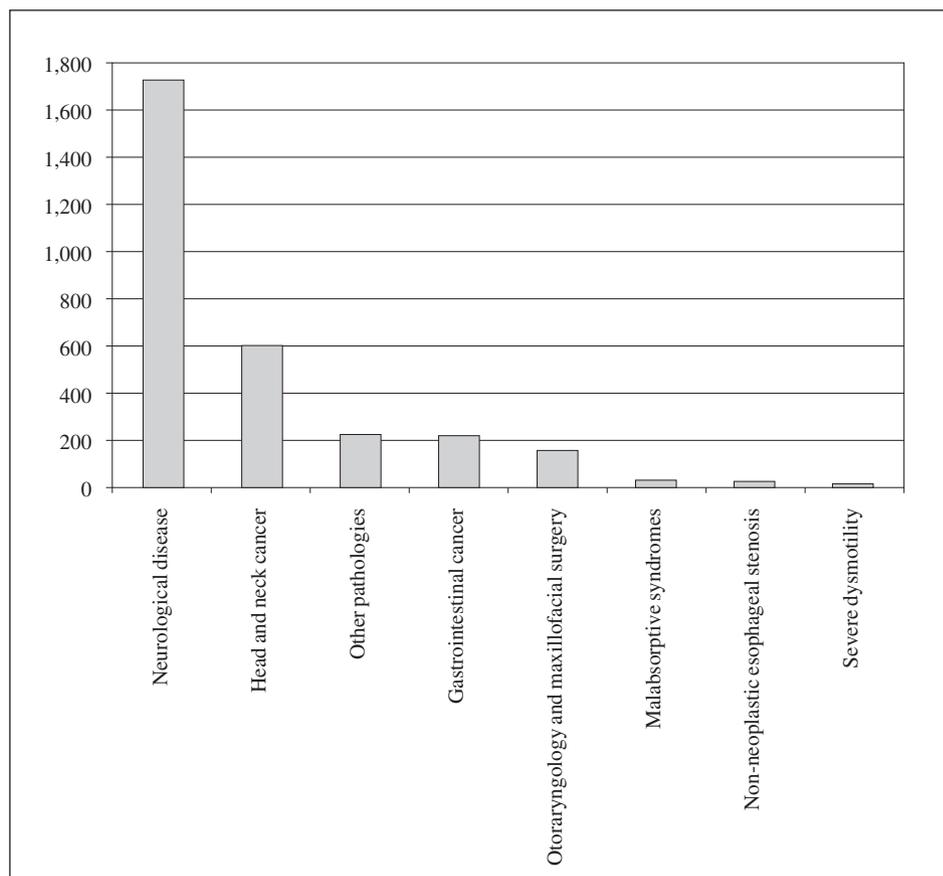


Fig. 2.—HEN associated diagnoses: 2011-2012 (n).

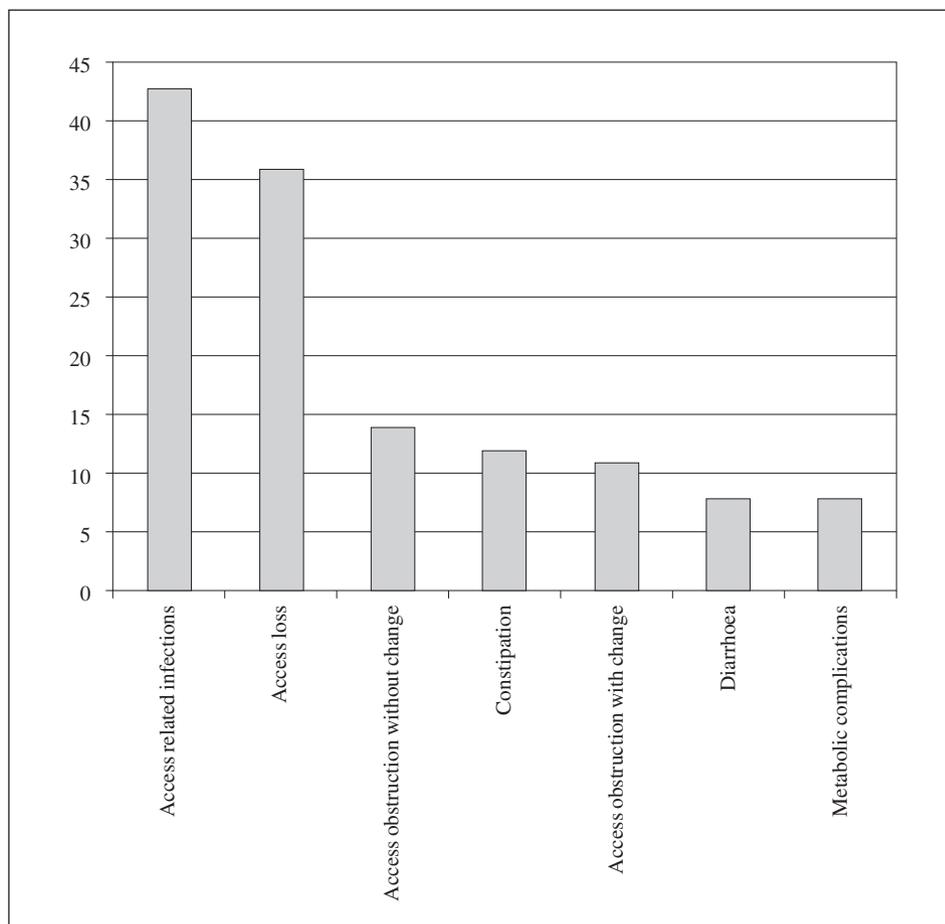


Fig. 3.—HEN registered complications: 2011-2012 (n).

scientific societies. Their aim is to give information and to create scientific knowledge in order to plan resources, compare and evaluate results in a specific situation<sup>23</sup>. NADYA-SENPE has contributed regularly to the communications of data in its registry since its beginning in 1992. In this study, we have chosen to report simultaneously two consecutive years. The analysis of any single year has not showed significant changes in tendency (data not shown).

Although total number of registries was above 3000 patients, it decreased since 2010 (over 6000 patients that year). The number of hospitals participating on the registry also decreased from 32 to 29 in these two years<sup>1</sup>. It is possible that the change and update of the database have contributed to these decreases. Although previous variables have been preserved, it was necessary a migration of previous data to the new database, but without including patients without recent update or with finished HEN. A similar effect was observed in 2004 by an operating change in the registry<sup>22</sup>. Furthermore, though in the database is already accessible oral HEN (over 1000 kcal of formula daily by this route), in practice only events which require a tube are registered. In the previous database, oral HEN was the route used by a relevant number of patients<sup>22</sup>. Anyway, the process of

updating the database improves the validity of data in these two years.

The frequency of HEN in Spain (over 60 per million people) must be taken cautiously, because it comes from a voluntary registry which does not include the real prevalence. Nevertheless, in 2007, the frequency of patients with HEN by tube was 41 per million people and we may conclude from this that the prescription of this kind of nutritional support seems to have been increased<sup>22</sup>. In Spain, several regional studies concerning the tendency in HEN, which agree to show an increase in the prescription of this nutritional support technique over the first decade of 21<sup>st</sup> century, have been communicated<sup>24</sup>, although some of these reports have concluded that this increase may have been due to oral HEN, while tube HEN has been constant<sup>25</sup>.

Our database scarcely includes a 2% of patients ages 14 or younger. The registry concerning enteral nutrition in Paediatrics (NEPAD), operating since 2003, includes more exhaustive information of children with HEN in Spain<sup>26</sup>.

The discrepancy in the frequency of reporting HEN among regions in Spain is observed repeatedly from the beginning of NADYA registry<sup>22</sup> and is maintained in the two years of the study.

The median age of the adults included in the registry was over 70 and, in fact, half of them were over 72. The evolution towards an increase in the age of subjects in the registry was already observed when the tendencies among the years 1992 and 2007 were analyzed (from 26% to 42% aged over 74, respectively)<sup>22</sup>. These data could be in line with the increase in life expectancy in our country<sup>27</sup> and, perhaps, with a delayed dependency during the course of life through the years, though it is also possible that the development of knowledge has made easier that this nutritional intervention could be prescribed in later stages of life when they were rejected previously (neurodegenerative diseases)<sup>28</sup>. The mean age described in 2010 was 69.9<sup>1</sup> and it could have been probably similar to the one we are reporting if it had been expressed as median because mean age in the period 2011-2012 was 67.6.

Median age in children registered was below 1 year, lower than the mean in 2010<sup>1</sup> and in the description of tendencies among 1992 and 1997 (means between 4 and 6 years)<sup>22</sup>.

Fifty percent of patients had HEN during almost one year. This observation disagrees once more with the data in 2010, when 76% of patients had HEN over 2 years<sup>1</sup>. The update of the registry seems to have provoked the erasure of patients who remained in the database though they did not have HEN any longer but the event was not closed. Nevertheless, the evolution towards an increase in the time of treatment is clear if we compare it to the data previously reported (6.3 months in 1994 and 9.4 months in 2007)<sup>22</sup>.

More than 95% of the patients had a single event with HEN, but it was reported more than one event in several patients, being sequentially less frequent up to five events with HEN in one patient.

The most common disease leading to the need of HEN was neurological disease, in adults as well as children (over 45% in both groups). The same situation showed the report of 2010<sup>1</sup>, with an increasing tendency since 1992 among adults (32%, 37%, 42% and 58% in 1992, 2007, 2010 and 2011-2012, respectively)<sup>22</sup>. Among children, the present data do not differ much from the data in NEPAD registry<sup>26</sup>.

Cancer was the second most common diagnosis linked to HEN. In this case, the evolution has been the opposite, with a tendency to decrease<sup>22</sup>, probably because there have been a lower report of oral HEN and higher of tube HEN. And so, in local reports in which oral HEN is more common, cancer is the diagnosis more linked to this kind of artificial nutritional support<sup>24</sup>. In other registries of HEN, neurological as well as neoplastic diseases were the most prevalent causes<sup>23</sup>.

Among children and the first events with HEN, nasogastric tube was the most common access route (more than 40% in both). Higher prevalence is shown in NEPAD registry<sup>26</sup> as well as NADYA-SENPE report of 2010<sup>1</sup> (over 50% in both). The results shown in the tendency of NADYA-SENPE registry in the period 1992-2007, regarding nasogastric tube prescription,

must be explained taking into account that the decrease in the proportion was achieved by an increase in the patients with oral HEN in the registry in those years<sup>22</sup>, which has now disappeared from the registry.

Among adults, from the second event with HEN on, gastrostomy was the most common access route employed (over 60% and 70% in second and third event and 100% in the fourth), fact that is a reflection of the usual practice of prescribing this route when HEN is extended in time<sup>29</sup>. Jejunostomy was little reported as access route in HEN in our registry.

Reported complications, only in adults, have been scarce. The most common one was the infection of the access, followed by the loss of the tube. Between 1992 and 2007, the most reported event was the change of the tube and digestive disturbances<sup>22</sup>. According to usual clinical experience and recent related studies, it can be stated that most of the complications of these patients have not been probably registered<sup>30</sup>.

Regarding physical activity, 50% of the patients were in a chair to bed life, proportion which has increased respecting previous reports of the registry<sup>1,22</sup>, in accordance with the increasing age of patients and a higher prevalence of neurological disease. In the same way, and in relationship with the autonomy level, most of the subjects in the registry needed whole help over 50%, in contrast with previous reports of 39%<sup>22</sup> and 42%<sup>1</sup>.

Over 70% of the patients included received nutritional formula from their chemist's office and supply of disposables was made, mostly, from hospitals. In 2010 this situation was different, with a 63% of formulae provided from hospitals and, although disposables were also provided from hospitals above all, Primary Care function in this was minimal (only 16%)<sup>1</sup>. Nevertheless, there is a great disparity among geographical areas, depending on the organization of their health systems.

During this period (2011-2012), a 34% of episodes were finished, most of them due to deceases, with a frequency repeated in previous reports<sup>1,22</sup>. Oral intake recovery was lower than 30%, so among children as among adults. This proportion was higher before 2007<sup>22</sup>. Again, aging population, predominance of tube HEN and neurological disease may explain these changes.

And so, NADYA-SENPE registry keeps on being a useful tool to estimate globally the tendency in the prescription of HEN in Spanish National Health System. Its limitations are: non-compulsory report, simplification of data to make it more accessible, the low report of complications, and the non-negligible proportion of loss of follow-up, apparent from previous years' reports.

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