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Resumen
Existen pocos datos sobre la evolución de la prevalencia de nutrición parenteral domiciliaria (NPD) en cada país. El grupo de Nutrición Artificial Domiciliaria y Ambulatoria (NADYA) de SENPE se encarga del registro de pacientes en España desde el año 1992.

Método:
Se evaluó retrospectivamente la actividad del registro en el periodo 1992-2003. Los datos se extrajeron de la base de datos de NADYA así como de las comunicaciones a congresos y publicaciones realizadas por el grupo. No se disponen de datos de los años 1993 y del periodo 1997-9.

Resultados:
La prevalencia anual se dobló desde 1992 hasta alcanzar los 86 pacientes en 2003. El número de centros que comunicaron pacientes pasó de 10 a 17 en este periodo. Como promedio, el número de pacientes por centro fue 5, aunque sólo un número reducido de centros controla más de 10 pacientes de forma habitual. La prevalencia de NPD en 2003 fue de 2,15 pacientes por millón de habitantes, con un ligero predominio de mujeres (1,6:1). La edad media al inicio de la NPD pasó de 42 años en 1992 a 51 en 2003. La enfermedad vascular isquémica o trombótica fue la causa más común en todo el periodo de estudio; la indicación por obstrucción intestinal por cáncer se mantuvo alrededor del 20%. Excepto el descenso en el número de pacientes con enfermedad de Crohn, el resto de indicaciones sufrió pocas variaciones en el tiempo. Se observó a lo largo del tiempo un leve aumento en el número de pacientes que recibían los servicios a través de una compañía comercial (11% en 1992; 17% en 2003). Para el periodo 2000-3 encontramos que se producía > 1 complicación por paciente al año, generalmente relacionadas con la NPD, aunque con una tendencia mayor a no necesitar ingreso hospitalario por este motivo.

Conclusiones:
Se ha observado un constante aumento en el número de pacientes y de centros con NPD. La prevalencia de NPD fue de 2,15 pacientes por millón de habitantes en 2003. No ha habido modificaciones sustanciales en las indicaciones, la provisión de material y el seguimiento en todo el periodo de estudio. La tasa de complicaciones relacionadas con la NPD continúa siendo elevada.

(Trasunto)

Original
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Abstract
There are very few data on trends in home parenteral nutrition (HPN) in different countries. NADYA is the committee of the Spanish Society for Parenteral and Enteral Nutrition that takes care of the Spanish registry since 1992.

Method:
A 12-year retrospective study of the activity of the registry was performed. The data were extracted from the NADYA’s database as well as from the publications and abstracts reported on a yearly basis since 1992. Data on years 1993 and 1997-9 were not available.

Results:
Yearly prevalence has more than doubled to 86 patients since 1992. The number of reporting centres went up to 17 in 2003 (10 centres in 1992) As an average, the number of patients per centre is 5. The prevalence in 2003 was 2.15 patients per million inhabitants. There are trends to increasing age at the time of the first indication (42 years in 1992; 51 in 2003). Ischemic and thrombotic vascular diseases were the most common underlying diagnosis in adults. Tunnelled central venous catheters were chosen in 2/3 of the patients. Only around 17% of the patients received support from home delivery companies (11% in 1992) There were more than 1 complication per patient and year, mostly HPN-related.

Conclusions:
We found a steadily increase in the number of reported patients and reporting centres over time. Prevalence went up to 2.15 patients per million inhabitants in 2003, still far behind the figures from other western countries. The NADYA registry allows a close follow-up of the evolution of HPN in Spain.

(Key words: Home parenteral nutrition. Intestinal failure. Home care. Registry.)

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Long-term total or complementary parenteral nutrition (PN) is required to preserve nutritional status when oral or enteral nutrition cannot provide protein-energy needs, especially in diseases which impair digestive function. When a patient does not need hospitalization but depends on long-term PN, home PN (HPN) is an alternative to prolonged hospitalization and is recognized as the best option for improving the quality of life of these patients within the constraints of the disease. There is an increasing need to know the incidence and prevalence of HPN in different European countries as well as the evolution of its use along time. NADYA (Nutrición Artificial Domiciliaria y Ambulatoria) was set up as a committee of the Spanish Society for Parenteral and Enteral Nutrition (SENPE) in 1992 to collect and analyze data pertaining to enteral and parenteral nutrition support in adults and children in the community. NADYA-SENPE is intended to provide an annual report and publish the data in the official journal of the society (Nutrición Hospitalaria).

NADYA is a voluntary registry and depends on the goodwill of reporters across the country. Although we recognize that there are variable shortfalls in some of the data due to underreporting or even missed data in several years we do consider it is worthy to present the trends on home parenteral nutrition (HPN) in Spain over a 12-year period. This is the purpose of this paper.

**Material and methods**

A 12-year retrospective study evaluating the characteristics of patients receiving HPN was performed. The data were extracted from the NADYA's database as well as from the publications or abstracts reported on a yearly basis from 1992 through 2003. Data include registration, length on HPN, underlying disease, type of venous access, infusion method, HPN providers, use of infusion pump, rate of complications, outcome and issues regarding physical activity, working status and ability to follow an oral diet. The rate of complications is reported as percentage and number of admissions related to the technique per year. Data on years 1993, 1997, 1998 and 1999 were not available. The initial registry was based in a paper format and switched to an online reporting through the website of the group in 1998 (www.nadya-senpe.es). Each one of the reporting physicians can access the registry by means of a personal login. As the data were recorded by the end of a year period, the prevalence was considered as the yearly prevalence.

**Results**

**Period prevalence 1992-2003**

Yearly prevalence has more than doubled to 86 patients since 1992. The number of reporting centres went up from 10 in 1992 to 17 in 2003. Within the period 2001-2003 there has been a 30% increase with almost the same number of reporting centres (figure 1). As an average the number of HPN patients per centre is 5. There are only a few centres with more than 10 patients currently on HPN. Interestingly there is not a uniform distribution of patients all over the country (figure 2).

Prevalence was 2.15 patients per million inhabitants in 2003. Gender distribution: 1.6:1, females to males. There is a trend to increasing age over the years: mean age in 1992 was 42 years versus 51 in 2003.

**Diagnosis and reasons for HPN**

Ischemic and thrombotic vascular disease is the most common underlying diagnosis for adults starting HPN. That means that short bowel syndrome is the predominant reason for HPN. Malignant obstruction represents around 20% of patients. Radiation enteritis and chronic intestinal pseudo-obstruction or other motility disorders represent the two following indications. There has not been any important variation in the indications over the years, except for Crohn's disease that decreased from near 20% at the beginning of the 1990's to < 5% in the last three years (table I).
Vascular access route
Tunnelled central venous catheters (Hickman lines) were chosen in two thirds of the patients. Percutaneous transient venous catheters used decreased from 40% at the beginning of the register to < 5% in 2003.

Infusion method
Most of the patients received the infusion overnight (cyclic TPN), although 14% of the patients received HPN in different schedules. Most of them used an infusion pump. The pump was provided by the hospital in all cases.

Use of commercial home delivery companies
Only around 17% of the patients received support from commercial home delivery companies, although the figures went slowly up from the 11% in 1992. Disposables (infusion lines, filters, etc.) were provided by the tertiary hospital in more than 80% and by the primary physician in 20%.

The monitoring and follow-up of the patients was mainly done by the HPN responsible team in the tertiary hospital in 90% of the patients. There were an average of 11.3 visits per year as outpatients.

Complications
The data on complications were only available for the period 2001-3. There were > 1 complication per patient and year (table II), most of them related to HPN. The total number of complications has remained stable during this period. Nevertheless the necessity for admission because of a complication went down to 1.6 admissions per patient and year in 2003 (2.05 in 2001).

Outcome
The evolution of the patients was as shown in table III (period 2000-2003), considering the clinical condition at the end of each year period.

Discussion
Although HPN is a well-established home care technology available since the early 1970s, its development was not uniform across different countries. During this period, several thousand patients have received this home therapy. Nevertheless there are few studies currently reporting modifications in practise over time.

In the United States of America the most extensive database on HPN was compiled through a National Home Parenteral and Enteral Nutrition Registry by providers of long-term HPN patients on a voluntary basis. The last report was published in 1995 and was based on data collected between 1985 and 1992. As the expense of collecting and correlating these data are significant plus the difficulty to obtain data due to the fact that HPN is supplied by numerous infusion providers, the North American HPEN Registry no longer collects this information. Partial data from one large home nutrition support provider has been recently published.

In Europe, the Home Artificial Nutrition Working Group of ESPEN has periodically published reports on HPN practice in different European Countries. Nevertheless in most of the countries the data were not obtained from national databases but from questionnaires filled in by HPN centres.

The British Association for Parenteral and Enteral Nutrition (BAPEN) set up in 1996 the British Artificial Nutrition Survey (BANS) to collect and analyze data pertaining to enteral and parenteral nutrition support in adults and children in hospital and in the community.
There are no other European registries available, at least in the long-term benefits from HPN. Except for acquired patients with incurable metastatic disease would gain need for conducting robust studies to identify which stable over the last five-year period. There is still a cation, between 17-20%. This percentage has remained indicating HPN. They represent between 20 and 30% of the most common underlying diagnosis for adults covered by the National Health System.

Commercial Home Care providers represent only about 15% of the total volume of HPN patients. The remaining 85% are elaborated and distributed from the electronic reporting was a way of simplifying the use of an HPN registry are an important national resource that the figures could be similar.

### Table II

<table>
<thead>
<tr>
<th>Complications non-related to HPN</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>– thrombotic</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>– electrolytic</td>
<td>5</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>– mechanical</td>
<td>10</td>
<td>11</td>
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</tr>
<tr>
<td>– infectious</td>
<td>44</td>
<td>34</td>
<td>52</td>
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</tbody>
</table>

### Table III

<table>
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<tr>
<th>Number of complications</th>
<th>2001</th>
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<th>2003</th>
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</thead>
<tbody>
<tr>
<td>135</td>
<td>136</td>
<td>138</td>
<td></td>
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</table>

### Table IV

<table>
<thead>
<tr>
<th>Outcome of HPN patients</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
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</thead>
<tbody>
<tr>
<td>Continue on HPN (%)</td>
<td>61</td>
<td>74</td>
<td>74</td>
<td>73</td>
</tr>
<tr>
<td>Lost of follow-up (%)</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Off HPN (%)</td>
<td>39</td>
<td>36</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>Number of patients</td>
<td>67</td>
<td>66</td>
<td>74</td>
<td>86</td>
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</table>

In our series the admission rate was 1.9 admissions per patient and year. The rate of complications related to the length of HPN. Nevertheless, during the period 2001-3 the number of complications was near 2 complications per patient and year. 2/3 of them were HPN-related. These complications can lead to increased hospitalizations and increased costs. In our series the admission rate remained fairly stable. It is of note that near 30% of our HPN population, all the other indications have no longer needed since the advent of new drug therapy, immunodeficiency syndrome (AIDS), where HPN is no longer necessary.
Home parenteral nutrition in Spain

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References