

Original

Trends in adult Home Parenteral Nutrition in Spain. 1992-2003

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Abstract

There are very few data on trends in prevalence 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.

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Key words: *Home parenteral nutrition. Intestinal failure. Home care. Registry.*

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TENDENCIAS EN NUTRICIÓN PARENTERAL DOMICILIARIA EN PACIENTES ADULTOS EN ESPAÑA: PERIODO 1992-2003

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.

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Palabras clave: *Nutrición parenteral domiciliaria. Fracaso intestinal. Atención domiciliaria. Registro.*

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 time¹. 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 availa-

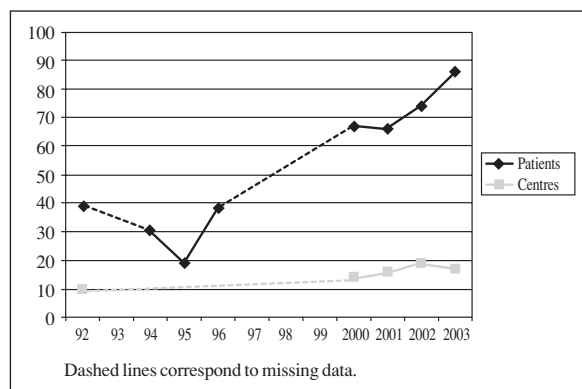


Fig. 1.—Adult HPN. Prevalence 1992-2003.



Fig. 2.—Distribution of HPN patients all over the country (data on 2003).

ble. The initial registry was based in a paper format and switched to an on-line 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 log-in. 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).

Tabla I
Diagnosis and reasons for HPN patients (data as percentage)

Year	Neoplasia	Radiation enteritis	Crohn	Motility disorder	Mesenteric ischaemia	AIDS	Others
1992	15	9	10	0	24	0	35
1993	–	–	–	–	–	–	–
1994	–	–	–	–	–	–	–
1995	10	26	21	10	16	10	7
1996	42	5	10	5	10	8	20
1997	–	–	–	–	–	–	–
1998	–	–	–	–	–	–	–
1999	–	–	–	–	–	–	–
2000	17	0	3	8	29	0	43
2001	23	12	5	5	29	0	26
2002	16	12	5	8	30	0	29
2003	20	16	5	10	20	0	29

Vascular access route

Tunnelled central venous catheters (Hickman lines) were chosen in two thirds of the patients. Percutaneous transient venous catheters use 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 1992². 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 published³.

In Europe, the Home Artificial Nutrition Working Group of ESPEN has periodically published reports on HPN practice in different European Countries^{4,5,6}. 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.

Tabla II
Complications in HPN patients (period 2001-3)

	2001	2002	2003
Number of patients	66	74	86
Number of complications	135	136	138
Complications related to HPN	86	94	98
– infectious	44	34	52
– mechanical	10	11	4
– electrolytic	5	3	6
– metabolic	7	22	16
– thrombotic	1	2	2
Complications non-related to HPN	49	42	40
Number of admissions per patient	2.05	1.84	1.60

They publish a well-documented report every year, and a periodical more extensive report^{7,8}. Executive summaries are available on the BAPEN website (www.bapen.org.uk). There are also occasional data from the Italian National register⁹. To our knowledge there are no other European registries available, at least in the bibliography resources commonly used. There are some other reports from Japan that only include partial data and, unfortunately, are published in Japanese¹⁰.

NADYA is a committee of SENPE that was set up in 1992 with similar objectives to BANS. Yearly reports have been published and are indexed in Medline in 1997, 1998, 1999, 2003, 2004 and 2005^{11,12,13,14,15,16}. In this 12-year period we could observe a steadily increase in the number of patients on HPN as well as in the number of centres, but still the figures are far behind the average in other Western countries. As HPN is not specifically regulated in Spain, there are no Specialized Service Providers for HPN. Interestingly, although there are no National Intestinal Failure Units, two centres have official approval to perform intestinal transplantation. Commercial Home Care providers represent only around 15% of the total volume of HPN patients. The remaining 85% are elaborated and distributed from the Hospital Pharmacy. All the expenses due to HPN are covered by the National Health System.

Ischemic and thrombotic vascular disease remained the most common underlying diagnosis for adults starting HPN. They represent between 20 and 30% of the indications. Malignant obstruction is the second indication, between 17-20%. This percentage has remained stable over the last five-year period. There is still a need for conducting robust studies to identify which patients with incurable metastatic disease would gain long-term benefits from HPN¹⁷. Except for acquired immunodeficiency syndrome (AIDS), where HPN is no longer needed since the advent of new drug therapy, and Crohn's disease that went down to less than 5% of our HPN population, all the other indications have remained fairly stable. It is of note that near 30% of registrations are reported as "Other". This definition requires clarification in the future.

The way the database was conceived does not allow knowing 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 was 1.9 admissions per patient and year. The rate of complications is above the average data from larger series¹⁸. It is important to emphasize that death on HPN therapy relates chiefly to a complication of the primary disease rather than a HPN complication. In the last three years none of the HPN patients died because of a HPN-related complication. Patient education, nursing technical expertise, and monitoring are vital components for preventing some of the most usual complications.

Most of the patients currently receiving HPN in Spain remain on the program longer than six months. HPN was withdrawn only between 25-40% of the patients by the end of the year. We can predict that if the rate of discontinuation continues so and no changes occur in the primary diagnosis, we will see a steadily increase in the number of HPN patients in Spain.

At this time, when the outcome for small bowel transplantation achieves survival rates up to 70 to 80% at 1 year and 50 to 60% at 3 years^{19,20} along with a clear indication for transplantation, it seems necessary to evaluate quality of life issues. Quality of life assessments need to include emotional, social, occupational, and physical parameters²¹. The NADYA-SENPE group is currently performing surveillance on the quality of life of Spanish HPN patients and their caregivers.

Cost-effective analysis including cost for quality of life achieved (quality-adjusted life year) showed that HPN costs 30 to 60% less than hospital parenteral nutrition and provides a better quality of life²². These results also apply for elderly patients or patients with underlying malignancy²³. Although we can not provide cost-effective analysis in Spanish patients, we assume that the figures could be similar.

NADYA-SENPE committee believes that the data of the HPN registry are an important national resource and the best available on a national basis. The use of an electronic reporting was a way of simplifying the

Tabla III
Outcome of HPN patients

	2000	2001	2002	2003
Number of patients	67	66	74	86
Continue on HPN (%)	61	74	74	73
Lost of follow-up (%)	0	0	3	3
Off HPN (%)	39	36	23	24
– death due to complication of HPN		0	0	0
– death because of other causes		14	12	13
– switch to oral/enteral diet		12	11	11

reporting process and ensuring more accurate data compilation and report generation. The on-line registry has been recently modified in order to get information not only on the point prevalence but in the period prevalence as well as incidence. This would allow obtaining complication rates more accurately.

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