

Original

Artificial Nutritional Support Registries: systematic review

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Abstract

Introduction: The nutritional registries are data bases through which we obtain the information to understand the nutrition of populations. Several main nutrition societies of the world have these types of registries, outstanding the NADYA (Home artificial and Ambulatory nutrition) group in Spain. The object of this study is to determine by means of a systematic review, the existent scientific production in the international data bases referred to nutritional support registries.

Methods: Descriptive transversal study of the results of a critical bibliographic research done in the bioscience data bases: MEDLINE, EMBASE, The Cochrane Library, ISI (Web of Sciences), LILACS, CINHALL.

Results: A total of 20 original articles related to nutritional registries were found and recovered. Eleven registries of eight countries were identified: Australia, Germany, Italy, Japan, Spain, Sweden, United States and United Kingdom. The Price Index was of 65% and all the articles were published in the last 20 years.

Conclusions: The Price Index highlights the innovativeness of this practice. The articles related to nutritional support are heterogeneous with respect to data and population, which exposes this as a limitation for a combined analysis.

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Introduction

Registries are data bases through which we obtain the precise information with respect to the characteristics, tendencies and behaviour of populations. They

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LOS REGISTROS DE SOPORTE NUTRICIONAL ARTIFICIAL: REVISIÓN SISTEMÁTICA

Resumen

Introducción: Los registros nutricionales son bases de datos a través de los cuales obtenemos la información para conocer los aspectos referentes a la nutrición de las poblaciones. Este tipo de registros no son frecuentes, aunque las principales sociedades de nutrición del mundo los tienen. La mayor representación en nuestro país la tenemos a partir del grupo NADYA (Nutrición Artificial Domiciliaria y Ambulatoria).

Objetivo: Determinar mediante revisión crítica la producción científica existente en las bases de datos internacionales sobre los registros de soporte nutricional artificial.

Métodos: Estudio descriptivo transversal de los resultados de las búsquedas bibliográficas efectuadas en diversas bases de datos.

Resultados: Se han encontrado 18 artículos relacionados con los registros nutricionales. En estos artículos se han identificado 9 registros de soporte nutricional.

Conclusión: Los registros encontrados, no son entre ellos homogéneos, presenta limitaciones importantes para extrapolar y comparar las diferentes poblaciones registradas.

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Palabras clave: Ciencias de la Nutrición. Registros. Apoyo Nutricional Artificial.

enable the knowledge of behaviours which provoke an increase or decrease of health and even effectiveness, efficiency and effectivity of the programs that are carried out to improve it.

A registry must have several characteristics which enable the estimation of the probability of certain results to occur in certain situations. These are: to have the capacity of reproducing the same results when obtained by the same method, in other words, being "reliable"; to obtain exactly what we want to, to be "valid"; to establish one unique definition criteria to make information unique, to be "homogeneous"; and to be able to obtain similar results when using the data

and criteria used by other researchers, in other words, to be “reproducible”.

The registries provide information that empowers the generation and actualization of science knowledge which enables the prevention and planning of resources facilitating the result’s evaluation and comparison.

This has an outstanding importance for patients since it helps us know the type of patient, situation, cause of indication, evolution and complication of those who receive Artificial Nutritional Support because they can’t feed themselves in a conventional way.

Traditionally it was a hospitalary treatment but, since a decade ago, it has been frequently administered in the patient’s home under the strong relieve that it could improve the patient’s and family’s quality of life, because they can have all the home comforts, facilitate the social integration and control of their own time. It also tries to improve the sanitary management.

Within this background, the interest for nutritional support registries emerged. These registries are not frequent, even though some of the most important societies of enteral and parenteral nutrition have them.

Focusing in Spain we find the work of the Ambulatory and Home Nutrition of the Spanish Society of Parenteral and Enteral nutrition group (NADYA-SENPE)¹ has been registering data of these patients since 1992 and offering an annual analysis of the registry as well as the tendencies observed in the last years in this type of therapeutic mode.

Objective

To know by means of a systematic review the different existent registries of artificial nutritional support and their main characteristics through the articles found in biomedical journals.

Methods

Descriptive transversal study of the results obtained from bibliographic research by means of a systematic review. The selection of the articles was done following the defined inclusion and exclusion criteria.

Inclusion criteria: The existence of any registry system of data related to Artificial Nutritional Support.

Exclusion criteria: The article must be obtained completely and they must come from original articles published by peers-journals.

Descriptors used

The study of the hierarquic structure of the Thesaurus “Medical Subject Heading Terms” (MeSH) considers appropriate the next descriptors:

“Registries”[MeSH]

“Forms and Records Control”

“Nutritional Support”[MeSH]

EMBASE required the use of the descriptors: register, disease registry and artificial feeding.

The most important biomedical databases where consulted (e.g. MEDLINE, EMBASE, The Cochrane Library, LILACS and ISI Web of Sciences). In EMBASE and MEDLINE, since they are the only bases that permit it, descriptors were used as *Major Topic* when they represent the most important concept of the article, submitting those which are less relevant.

Searching equations

(“Registries”[MAJR] OR “Forms and records control”[MAJR]) AND “Nutritional Support”[MAJR].

EMBASE

(‘register’/exp/mj OR ‘disease registry’/exp/mj) AND (‘nutritional support’/exp/mj OR ‘artificial feeding’/exp/mj).

The Cochrane Library

(Registries expand all trees (MeSH) or forms and records control expand all trees(MeSH)) and nutritional support expand all trees (MeSH).

ISI - Web of Sciences.

(TS=(Records as Topic) OR TS=(Forms and records control) OR TS=(Registries)) AND TS=(Nutritional Support).

LILACS

(“Sistema de registros”(DeCS) OR “Control de formularios y registros”(DeCS)) AND “Apoyo Nutricional”(DeCS).

All the equations used the limit “Humans”. This review took place by systematic review: consulting the most pertinent descriptors, their definition and hierarchic in the Thesaurus, with the purpose of reducing as much as possible the publication bias. Consequently, the replication of this work can be reproduced and actualized by “copy and paste” in an adequate database using the proposed equation for the research.

Additionally, and as a secondary search, the list of the related articles of the bibliographic selection was reviewed to identify those studies which were not detected by the electronic search.⁶⁻⁷

Similarly, the subject’s grey literature was consulted with the use of Scholar Google and Windows Live Search. Peer-reviewed comprehensive searches were conducted up to April 2008 in biomedical electronic databases.

Journal	Authors	Name of the Registry	Entities	Country	Language	Periodicity
<i>J Can Diet Assoc</i> 1987; 48 (3): 172-5	V. Albert et al.	ENMP	RVH	Canadá	English	Not specified
<i>Hosp Pharm</i> 1993; 28: 1065-75	K.P. Speight et al.	Parenteral Nutrition Order Form	WMC	USA	English	Continues
<i>Pharmacoeconomics</i> 1994; 5 (2): 101-8	M. Malone	Registro OASIS/ Oley Foundation Register UK HPN Register/ N A HPEN Register	Oley-ASPEN	USA	English	Annual
<i>Transpl Proc</i> 1998; 30 (1): 2529-30	T. Azuma et al.	Japanese HPN Registry	Japanese Society for HPN	Japan	English	1991-1994
<i>J Am Diet Assoc</i> 1999; (4): 467-470	CA. Braunschweig	Nutrition Registry Form	CMC-UI	EEUU	English	Annual 1997
<i>Nutr Hosp</i> 1999; 14 (4): 145-52	C. Gómez Candela et al.	NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 1996
<i>J Paediatr Child Health</i> 2000; 36: 472-6	M. Sharp et al.	BDRWA	PMHC	Australia	English	10 años (1986-1996)
<i>Nutr Hosp</i> 2003; 18 (1) 29-33	M. Planas et al.	Registro NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2000
<i>Nutr Hosp</i> 2003; 18 (1): 34-8	M. Planas et al.	Registro NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2000
<i>Nutr Hosp</i> 2004; 19 (3): 139-43	M. Planas et al.	Registro NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2001
<i>Nutr Hosp</i> 2004; 19 (3): 145-9	M. Planas et al.	Registro NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2001
<i>J Neurol</i> 2004; (251): 813-7	R. Forbes et al.	Scottish MND Register	SOHD	United Kingdom	English	1989-1998
<i>Nutr Hosp</i> 2005; 20 (4): 249-53	J. M. Moreno et al.	Registro NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2002
<i>Nutr Hosp</i> 2005; 20 (4): 254-8	M. Planas et al.	Registro NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2002
<i>An Pediatr</i> 2006; 64(3): 239-43	J. M. Moreno Villares et al.	NEPAD	SEGHNP	Spain	Spanish	Annual 2003
<i>Nutr Hosp</i> 2006; 21 (1): 71-4	M. Planas et al.	NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2003
<i>Euro J Clin Nutr</i> 2006; (1): 58-61	G. Violante et al.	Registro SINPE	SINPE	Italy	English	Triannual 2000-2002
<i>Z Gerontol Geriatr</i> 2007; 40 (1): 21-30	R. Wirth et al.	GEMIDES Datenbank	FACGF	Germany	German	Annual 2004
<i>Nutr Hosp</i> 2007; 22 (3): 307-12	C. Cuerda et al.	NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	Annual 2004 2005
<i>Nutr Hosp</i> 2007; 22 (4): 491-5	C. Cuerda et al.	NADYA-SENPE	Group NADYA-SENPE	Spain	Spanish	10 last years

Independent variables of the study: journal, author, registry, entity, country, language, publication period, number of patients included in the registry, main result, publication year.

Dependent variables: Price Index (percentage of articles published under or in five years) and obsolescence (number of years in which a bibliographic reference remains valid, during the moment of the study: "mean age" (lowest mean age is the value of the period of time during which half of the bibliography remains active, considering active the fact of being cited in the bibliographic references)).

Results

The research made in the different databases gave as a result 22 articles.^{1-5, 8-19, 25-29} The search made in MEDLINE included all the articles found in EMBASE. The bibliographic list of articles distinguishes 18 pertinent references, which were included once completing the inclusion criteria. The rest of the documents included were related articles.

Four articles were denied since they don't follow the inclusion criteria because they are not original articles (table I).

Documental description

The selected articles show a median age, or obsolescence, of 4 years with a range of 20 years being published between 1987 and 2007 (fig. 1). The median of the publication date was found in 2004. The distribution of the article's publishing date showed two modal peaks; one in 2004 and another in 2007, each publish-

Table I
Bibliographic search research

Data Bases	Localized Articles	Recovered Articles	Denied Articles
MEDLINE	21	21	3 ^{A,B,C}
EMBASE	8	8	-
The Cochrane Library	1	1	1 ^D
ISI (Web of Sciences)	3	3	1 ^D
LILACS	0	0	

^A Hoernle E. *Hosp Formul* 1991; 26 (12): 972-3.

^B Stokes MA et al. *N Z Med J* 1989; 102 (878): 568.

^C Norderström J et al. 1989; 86 (21): 2027-8.

^D Vernon-Roberts A et al. Cochrane Database of Systematic Reviews (1) Art No. CD006151 2007.

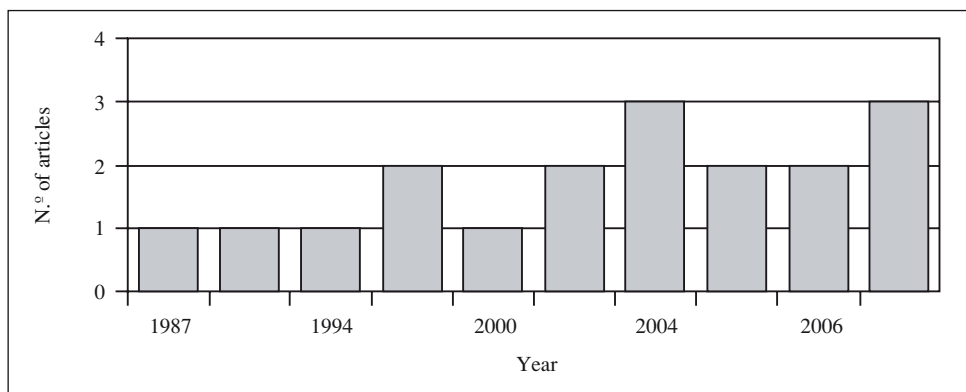


Fig. 1.—Years of publication of the articles.

ing 3 articles. The Price Index is of 65%. The languages in which these articles were published were: English 8 (40%), Spanish 11 (55%) and German 1 (5%).

Nine registries have been identified in the first review; the related articles provided two other new registries in Japan and Italy (table II).

The entities responsible for these registries are mostly scientific societies: SENPE; SINPE, Oley-ASPEN (Oley-American Society of Parenteral and Enteral Nutrition), SEGHN (Sociedad Española de Gastroenterología, Hepatología y Nutrición Pediátrica), FACGF (Federal Association of Clinical Geriatric Facilities), Japanese Society of Home Parenteral Nutrition. Each one was responsible for one registry. Two of the identified registries depended of hospital entities.

Scientific society registries generated 75% of the articles (15). Within them, NADYA-SENPE was responsible of 50% (10), all published in «*Nutrición Hospitalaria*», OLEY-ASPEN of 5% (1), as well as SEGHN, SINPE, SJNPD and FACGF. Those belonging to hospital entities generated a 25% (5).

Table II
Identified registries

1. Oley Foundation Register.
2. United Kingdom Home Parenteral Nutrition Register (UK HPN R).
3. North American Home Parenteral and Enteral Nutrition Register (NA HPEN R).
4. NADYA-SENPE Register.
5. Birth Defects Register of Western Australia (BDR WA).
6. Scottish Motor Neuron Disease Register (Scottish MND R).
7. Home and Ambulatory Pediatric Enteral Nutrition (NEPAD).
8. Geriatric Minimum Data Set (GEMIDES).
9. Sverige Central Register (SCR).
10. Italian Society of Enteral and Parenteral Nutrition (SINPE) Register.
11. Japanese Register of Enteral and Parenteral Nutrition.

Methodological description

All publications use a descriptive prospective design of different periods of time, outstanding that 65% (13) have been annual, 17% (3) published their information every 10 years, 5% were each three years 5% (1). There is no information of the period of time covered by the study in 10% of the articles (2).

The number of patients included in each article is not specified in 5 articles (28%).

With respect to the type of nutritional support used, enteral nutrition is found in 13 articles (40%) and parenteral nutrition in 18% (60%), taking into consideration that 8 of them refer to both artificial nutritional supports simultaneously.

Ten of the 20 articles^{6, 11-19} mention the mean age of the patients. Enteral nutrition presents a mean of 62.0 ± 8.5 years (y) in adults and 5.6 ± 0.4 y in children. Parenteral nutrition presents a mean age of 51 ± 2.2 y in adults and 5.1 ± 1.9 y in children.

These same ten articles mentioned the mean of the period of treatment having 6.3 ± 0.4 months (mo) in enteral nutrition and 8.2 ± 0.6 mo in parenteral nutrition.

The most frequently registered diseases responsible of home enteral nutritional support were neurological and neoplastic, followed by gastrointestinal. In home parenteral nutrition, mesenteric ischemia diseases predominate, followed by neoplastic diseases.

In terms of vias used the most used is the oral via, with a dominance of the polymeric formulas. In parenteral nutrition, the use of tunneled catheters seems to be the most frequent.

Discussion

There are not many studies in the scientific literature dealing with the artificial nutrition support registries, and those existing are heterogeneous as much as we can observe in our results. This represents an important limitation to analyse deeply the data published in them since there is no possibility of comparison.

Evidence in this study has supported the existence of eleven nutritional support registries. Other authors¹

identify less number of registries without mentioning the Australian,² Canadian,³ Swiss⁴ and the German⁵ registry.

Registries present limitations respect to the data they collect. In fact, this is the main argument of several researchers²⁰ who lead initiatives to update, or even develop, new registries seeking the improvement of the activity of the centre of home nutritional support to achieve homogeneity in the clinic-assistant behaviour stating that the existent registry is not completing the clinic's requirements. Moreover, the increase in the diffusion of home nutritional support does not show a parallel increase in its registry's improvement, which makes it difficult to obtain representative information.²⁹

Evidence has proved that the age of the articles found is very short, with a high Price Index. This fact is understood, not only because artificial nutrition is a relatively recent practice but because most of the articles found register home nutritional support and this is a very novel type of clinical assistance.

The German registry (Gemidas Datenbank) Works with the biggest nutritional support database in Europe²¹ and, despite its use in only geriatric patients; it has an important participation and uses an innovative software. In the other hand, those who use it outstand that modifications are required and that a more detailed analysis could be obtained out of it.²² C. Irelton-Jones et al. 2005 comments that there are few works about registries of patients receiving parenteral nutrition, probably due to the lack of demand of this information to the service provider companies. It has been estimated that 39,000 individuals receive parenteral nutritional support each day in USA, nevertheless few studies have evaluated and presented the results of this patients and there is an insufficient availability of data about them. These authors try to explain this fact due to the abundance of prescriptors and providers, and due to the high cost of maintenance to collect and work this data.²³ Maybe registries could have the answer to the demand of sanitary management services, being an instrument that clinics could use to influence sanitary administrations to normalize this practice in different care settings.

The majority of articles of registries of nutritional support found in this study have been published by "Nutricion Hospitalaria". The reason is that this journal is SENPE's expressing media, and this group is the one with more scientific production, since they publish their data annually.

Registries collect valid clinic information but its maintenance and evolution require help and infrastructure which is not easily found. Some European countries have financial programmes for the consolidation of multicentric registries, aiming their conversion into Official Sanitary Registries. In our opinion, which coincides with that of Iglesias et al. 2005, the implantation of this type of programmes could be interesting for the different countries.²⁴

The conclusions we reach through the results of this study are that the articles minding nutritional support are heterogeneous with respect to the data, handling and purpose of each registry, being this a limitation for the analysis.

As we can observe in the Price Index, these registries are a relatively new mode that probably still needs more maturation.

As a recommendation, we consider that a valid option to improve nutritional registries would be to convert them into mixed registries. In this way, only a small number of obligatory data would be demanded for all the sanitary centres and this would enable the access to the most basic and representative data of the population with this type of treatment. In the same way, other voluntary data, added by those who have more time or subject implication, could increase the knowledge of artificial nutritional support in Europe.

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