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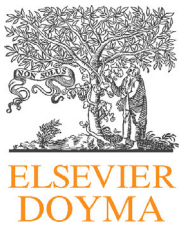

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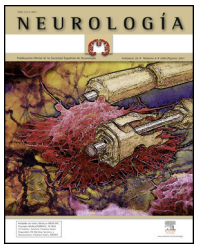

ORIGINAL ARTICLE

Changes in the demand for paediatric neurology care in a Spanish tertiary care hospital over a 20-year period☆

L. Monge Galindo[a,*], J. López-Pisón[a], P. Samper Villagrasa[b], J.L. Peña Segura[a]

[a] *Unidad de Neuropediatría, Hospital Universitario Miguel Servet, Zaragoza, Spain*
[b] *Universidad de Zaragoza, Zaragoza, Spain*

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Abstract
Objective: The purpose of this study is to determine the profile of the demand for paediatric neurology care in a Spanish tertiary hospital over the past 20 years.
Method: We studied epidemiological data, reasons for consultation, diagnoses and complementary tests from all patients examined by our Paediatric Neurology Unit in its 20 years of service (from May 1990 to March 2010). We also reviewed data from patients whose first visit took place within the last five years (2005—2010) and compared them to data obtained from a prior study carried out in this Unit from 1990 to 1995. To compare the first 5 years (group 1) with the last 5 years (group 2), we calculated confidence intervals, $P < .05$, for the frequency distribution (%) in each category.
Results: Main reasons for consultation and principal diagnoses for the 12 726 patients evaluated in the 20-year period, as well as results from group 1 (2046 patients) and group 2 (4488 patients) corresponding to first and the last 5 years of activity respectively, are presented with their confidence intervals in a series of tables.
Conclusions: Variations in the reasons for consultation, diagnoses and complementary tests over time reflect changes determined by medical, scientific and social progress, and organisational changes specific to each hospital. This explains the difficulty of comparing different patient series studied consecutively, which are even more pronounced between different hospitals.

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* Corresponding author.
E-mail address: pediatriazaragoza@hotmail.com (L. Monge Galindo).

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PALABRAS CLAVE
Actividad asistencial;
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Neuropediatría

Evolución de la demanda asistencial neuropediátrica en un hospital español de tercer nivel a lo largo de 20 años

Resumen
Objetivo: El objetivo de este trabajo es conocer el perfil de la demanda asistencial neuropediátrica en un hospital español de tercer nivel a lo largo de los últimos 20 años.
Método: Se estudiaron datos epidemiológicos, motivos de consulta, diagnósticos y exámenes complementarios de todos los pacientes valorados en nuestra Unidad de Neuropediatría en sus 20 años de funcionamiento (de mayo de 1990 a marzo del 2010). También se revisaron estos mismos datos centrándonos en pacientes cuya primera visita se efectuó en los últimos 5 años (2005—2010), para compararlos con los obtenidos en un estudio previo desarrollado de 1990 a 1995 en esta unidad. Para comparar los 5 primeros años (grupo 1) con los últimos 5 años (grupo 2), se calcularon los intervalos de confianza para $p < 0{,}05$ para la distribución en frecuencias (%) de cada categoría.
Resultados: Los principales motivos de consulta y diagnósticos de los 12.726 pacientes valorados en los 20 años, así como los resultados obtenidos del grupo 1 (2.046 pacientes) y del grupo 2 (4.488 pacientes), con sus intervalos de confianza, se presentan en diversas tablas.
Conclusiones: Las variaciones experimentadas en los motivos de consulta, los diagnósticos y los exámenes complementarios a lo largo del tiempo reflejan los cambios determinados por los avances médicos, científicos y sociales, además de temas organizativos propios de cada hospital, lo que explica las dificultades para comparar diferentes series de pacientes en diferentes momentos y más aún entre diferentes hospitales.

Introduction and objectives

As with all other disciplines, paediatric neurology care should be organised based on the real needs of a population, which vary depending on technical, scientific, and social advances. Apart from contributing to improved distribution of resources, studies focusing on paediatric neurological diseases will foster the development and study of the specialty and also clarify specialists' needs and those aspects that should be improved during their training.

The scientific literature includes few studies on the demand for neuropaediatric care. Most of them were carried out in Spain, and before 2005: Martínez-Menéndez et al.[1] and Mateos et al.[2] in Madrid, Garaizar et al.[3,4] in the Basque Country, and López-Pisón et al.[5–8] in Zaragoza, all in tertiary hospitals; and also Herrera et al.[9] in Segovia and Peña-Segura et al.[10] in Guadalajara, in secondary hospitals.

The aim of this study is to profile the demand for paediatric neurology care in a tertiary hospital over the last 20 years.

Materials and methods

This article presents a retrospective and descriptive study of paediatric neurology care at Hospital Infantil Universitario Miguel Servet, Zaragoza (Spain), the centre of reference for Aragon, La Rioja, and Soria, spanning the last 20 years; this study mainly focused on diagnosis rather than treatment.

The healthcare interventions provided by this unit since it first opened in 1990, along with all known and relevant patient data included in the study, were recorded in a digital database (Microsoft Access 2000). We identified 66 different reasons for consultation, 312 diagnoses, and 59 complementary tests (of which 26 were genetic studies).

We analysed the epidemiological data, reasons for consultation, diagnoses, and complementary tests from all patients assessed by our unit throughout its 20-year history (from May 1990, when the Paediatric Neurology Unit was launched, until March 2010). The unit assessed a total of 12 726 patients. In addition, we reviewed these data by focusing on patients whose first visit took place during the past 5 years (2005—2010) so as to compare them with data from the study by López Pisón et al.[5–8] carried out during our Paediatric Neurology Unit's first 5-year period (1990—1995). This approach aims to determine tendencies over time.

We calculated the confidence intervals for $P < .05$ for the frequency distributions (%) corresponding to each category in order to compare data from the first 5 years (group 1) with those from the last 5 years (group 2).

Statistical analysis was performed with the Statistical Package for Social Sciences programme, version 16.0.

This study was approved by the Clinical Research Ethics Committee of Aragon during their meeting on 27 May 2010.

Results

During the 20-year study period, 12 726 patients received neuropaediatric care, which represents a mean of 636.3 new paediatric patients yearly. Among them, 7103 were males (55.81%) and 5623 were females (44.19%). The mean number of new children per year was 409.2 for group 1; this figure was twice as high in group 2 (897.6 new children/year).

Mean age $\pm$ standard deviation at the time of the first visit was 5.6 ± 4.7 years. Among patients attending an initial consultation, 60% were younger than 6. Only 21.7% of our patients were assessed before the age of 12 months.

A total of 4957 children (39%) were referred for neurological assessment after admission to hospital, 4419 (35%)

Table 1 Main reasons for consultation (from high to low frequency) in the 12 726 patients assessed in the 20 years that the Paediatric Neurology Unit has been operational. This table also shows the same data for group 1 (2046 patients) and group 2 (4488 patients) that correspond to the first and last 5 years of that period, respectively (confidence interval and level of statistical significance set at $P < .05$).

Reasons for consultation	20 years, 1990–2010 ($n = 12\,726$)	Group 2: last 5 years, 2005–2010 ($n = 4488$)		Group 1: first 5 years, 1990–1995 ($n = 2046$)	
	%	%	Confidence interval	%	Confidence interval
Paroxysmal disorders	37.91%	34.69%	33.30%–36.08%*	40.00%	37.88%–42.12%*
Headache	21.01%	27.30%	26.00%–28.60%*	9.00%	7.76%–10.24%*
Psychomotor retardation	9.93%	10.41%	9.52%–11.30%	9.90%	8.61%–11.19%
Cranial trauma	5.65%	2.94%	2.45%–3.43%*	9.60%	8.32%–10.88%*
Perinatal problems	4.88%	2.87%	2.38%–3.36%*	9.20%	7.95%–10.45%*
Changes in shape and size of the head	4.83%	5.82%	5.14%–6.50%*	3.27%	2.50%–4.04%*
Gait disorder	3.66%	3.65%	3.10%–4.20%	3.00%	2.26%–3.74%
Behavioural problems	3.06%	2.72%	2.24%–3.20%*	1.60%	1.06%–2.14%*
Paresis	2.56%	2.12%	1.70%–2.54%*	3.70%	2.88%–4.52%*
Educational problems	2.55%	3.23%	2.71%–3.75%*	0.60%	0.27%–0.93%*
Pain	2.31%	1.80%	1.41%–2.19%	2.40%	1.74%–3.06%
Acute encephalopathy	2.28%	1.65%	1.28%–2.02%*	3.00%	2.26%–3.74%*
Hypotonia	1.97%	2.16%	1.73%–2.59%	1.40%	0.89%–1.91%
Facial paresis	1.83%	1.74%	1.36%–2.12%	1.60%	1.06%–2.14%
Torticollis	1.50%	1.49%	1.14%–1.84%	1.50%	0.97%–2.03%
Tics	1.46%	1.60%	1.23%–1.97%*	0.60%	0.27%–0.93%*
Cutaneous spots	1.39%	1.54%	1.18%–1.90%	0.80%	0.41%–1.19%
Lack of motor coordination	1.21%	1.23%	0.91%–1.55%	0.60%	0.27%–0.93%
Attention deficit	1.13%	2.70%	2.23%–3.17%	–	–
Language disorders	0.98%	1.00%	0.71%–1.29%	0.50%	0.19%–0.81%

–: Data not available.
* Statistically significant, $P < .05$.

were referred by their primary care paediatrician, and the remainder came from other centres.

At the time of the first visit, 31.6% of the children were discharged. The rest of the patients had a mean follow-up time of 2.2 ± 3.05 years. Of the patient total, 1.9% (244) died and 8.2% (1041) needed to be admitted to the paediatric intensive care unit.

Table 1 shows the main reasons for consultation for the 12 726 patients assessed in the unit's 20-year history, with a comparison between group 1 (2046 patients) and group 2 (4488 patients). The same data, broken down by main diagnostic categories, are displayed in Table 2.

We should highlight that 13% (1663) of the children had prenatal encephalopathy, among which 76% were not assigned an aetiological diagnosis. Functional diagnosis of these patients was as follows: overall psychomotor retardation/intellectual disability (51.1%), autism spectrum disorders (19.1%), and cerebral palsy (24.3%). Epilepsy was also present in 18.9% of these children.

No complementary tests were requested for 1068 patients (8.4%) since their detailed medical histories and physical examinations provided sufficient information. Brain MRIs were performed on 11.7% of the patients in group 1; this percentage increased to 37.5% in group 2 (the last 5-year period). Genetic studies were performed on 11.9% in group 1 and 32.2% of the patients in group 2. Between September 2009 and March 2010, we carried out a total of 68 analyses using microarray-based comparative genomic hybridisation (array-CGH) in patients with a peculiar phenotype and overall psychomotor retardation/intellectual disability. A total of 18 patients (26.5%) presented alterations accounting for these symptoms.

Discussion

Reasons for consultation, diagnoses, and complementary tests evolved over time, which reflects changes resulting from medical, scientific, and social advances, in addition to each hospital's organisational characteristics. These differences may explain the difficulties of comparing different patient series at different moments and especially between different hospitals.

Demand for neuropaediatric care increased during the 20-year study period, doubling over the last 5 years to yield a mean of 636.3 new paediatric patients per year.

This demand largely originates in the hospital (39% of the patients assessed during the 20-year study period) due to in-hospital consultations and assessments performed in different outpatient clinics and hospital wards, making paediatric neurology a hospital-based specialty. However, our

Table 2 Main diagnostic groups (in descending order of frequency) of the 12 726 patients assessed in the 20 years that the Paediatric Neurology Unit has been operational. This table also shows the same data from group 1 (2046 patients) and group 2 (4488 patients) corresponding to the first and last 5 years, respectively (confidence interval and level of statistical significance set at $P < .05$).

Main diagnostic groups	20 years, 1990–2010 ($n = 12\,726$)	Group 2: last 5 years, 2005–2010 ($n = 4488$)		Group 1: first 5 years, 1990–1995 ($n = 2046$)	
	%	%	Confidence interval	%	Confidence interval
Paroxysmal disorders	41.17%	31.62%	30.26%–32.98%*	43.70%	41.55%–45.85%*
Non-epileptic paroxysmal disorders	23.87%	18.27%	17.14%–19.40%	19.00%	17.30%–20.70%
Epilepsies	9.22%	6.82%	6.08%–7.56%*	15.40%	13.84%–16.96%*
Febrile convulsions	8.08%	6.53%	5.81%–7.25%*	12.40%	10.97%–13.83%*
Headache	20.59%	27.05%	25.75%–28.35%*	7.80%	6.64%–8.96%*
Prenatal encephalopathy	13.08%	12.61%	11.64%–13.58%	12.40%	10.97%–13.83%
Grouped rare diseases	12.11%	10.18%	9.30%–11.06%*	15.54%	13.97%–17.11%*
Head trauma-other accident	6.64%	3.48%	2.94%–4.02%*	11.10%	9.74%–12.46%*
Infectious and autoimmune diseases	4.30%	4.08%	3.50%–4.66%*	6.00%	4.97%–7.03%*
Movement disorders	3.91%	3.43%	3.31%–4.45%	3.10%	2.35%–3.85%
Perinatal encephalopathy	3.12%	2.14%	1.72%–2.56%*	6.40%	5.34%–7.6%*
Somatoform and factitious disorders	2.59%	2.14%	1.72%–2.56%	–	–
Tumours	1.75%	1.02%	0.73%–1.31%*	3.10%	2.35%–3.85%*
Neuromuscular diseases	1.73%	0.94%	0.66%–1.22%*	3.10%	2.35%–3.85%*
Neurocutaneous syndromes	1.29%	1.34%	1.00%–1.68%	1.20%	0.73%–1.67%
Metabolic diseases	1.08%	0.67%	0.43%–0.91%*	3.30%	2.53%–4.07%*

–: data not available.
* Statistically significant, $P < .05$.

experience showed that this percentage is closely followed by the demand for paediatric neurology care arising from primary care centres (35%).

Most of the consultations correspond to newborn and unweaned infants; infants younger than 12 months account for 21.7% of the total, a figure which resembles rates from other series.[10] This is probably due to the fact that this age group poses the most difficulties during examination. Alterations may be subtle (for example, changes in social contact or in muscle tone); often, they can only be diagnosed by professionals trained in neuropaediatric examination. In some cases, frequent monitoring is the only means of guaranteeing appropriate neurological development considering the variations in the normal range.

Paroxysmal disorders were the main reason for consultation during the entire study period (38% of the total). They represent an important topic in paediatric neurology in view of the high number of cases and the considerable variety and transcendence of the problems that they generate. A detailed history of the episode, emphasising the possible triggers, is necessary if we are to avoid diagnosing epilepsy erroneously.[11] Paroxysmal attacks are the main reason for consultation. As such, they also constitute the main diagnostic group which includes epilepsy, febrile convulsions, and non-epileptic paroxysmal disorders. In our experience, the number of non-epileptic paroxysmal disorders did not vary over the years. Febrile convulsion cases have decreased with the knowledge that simple febrile convulsions have a good prognosis and do not require complementary tests or treatment.[12] A total of 1173 patients presented epilepsy, which was symptomatic in 44% of the cases. We believe that the difference between percentages of epileptic patients between the two periods (15.40% in group 1 and 6.82% in group 2) does not reflect decreasing epilepsy rates. Rather, the rate in the first 5 years accounts for those patients whose epilepsy manifested in that period, plus those diagnosed before our unit became operational and who had previously been monitored by other specialists (paediatricians, neurologists, general practitioners, etc.).

Next in frequency after epilepsy are headaches, which showed a significant increase (27% of our population). This finding has been described by prior studies.[13,14]

The third reason for consultation was psychomotor retardation, which remained stable at about 10% of the total. Changes in head size and shape increased (especially regarding plagiocephaly), probably because of the American Paediatric Academy recommendations (1992) which advise placing unweaned babies in the supine decubitus position to sleep in order to reduce the risk of sudden infant death syndrome.[15] According to results regarding reasons for

consultation, educational problems, behaviour disorders, and attention deficit (hyperactivity) disorder also increased. This was especially true of attention deficit (hyperactivity) disorder since most cases came from the last 5-year period and none were recorded in the first 5 years. This shift is also described in the scientific literature, and it is reflected in the numerous articles on this topic that have been published in recent years.[16,17] Head trauma and perinatal injury decreased, while gait disorder figures remained stable.

Of the patient total, 12% of the cases were diagnosed with rare diseases. Most of these were classified as neuromuscular diseases, neurocutaneous syndromes, metabolic diseases, and some types of epilepsy. Rare diseases are decreasing due to breakthroughs in genetic studies and prenatal diagnosis.

Somatoform and factitious disorders frequently lead to consultations in paediatric neurology practice. These disorders should be suspected in patients, mainly girls aged 6 and older, who report multiple and varied symptoms. Several tests may be needed in order to rule out organic causes.[18]

Neuropaediatric care burden increases when doctors are involved in treating children admitted for potentially serious problems, such as head trauma and other accidents (6.6%), infectious and autoimmune diseases (4.3%), perinatal encephalopathy (3.1%), and acute encephalopathy (2.3%). The severity of some of these problems is reflected by the admission rate to the intensive care unit (8.2%), as well as the volume of deaths (1.9%).

Although the scientific literature includes few studies of demand for paediatric neurology care in tertiary hospitals, most authors agree that headache and epilepsy are the most frequent diseases. [1,4] This finding was also described in our series. However, making other comparisons is complicated, since the different studies (including our study) did not use a uniform method of constituting diagnostic groups.

Brain MRI was performed in 11.7% of the cases in group 1; this percentage increased to 37.5% in the past 5 years (group 2). At present, CT scans are reserved for emergency situations.

Genetic testing was employed in 11.9% of the cases in group 1 and 32.2% of the cases in group 2. Many genetic studies have established a firm diagnosis, thereby eliminating the need for biopsy in various neuromuscular diseases. They have also yielded early diagnoses of processes with no other biological markers (including forms of epilepsy such as Dravet syndrome). Furthermore, they have also proved their reliability in systematic diagnostic strategies or processes that investigate overall psychomotor retardation/intellectual disability.

The use of array-CGH is an example of a genetic advance in paediatric neurology. Between September 2009 and March 2010, we performed 68 array-CGH analyses in patients with a peculiar phenotype and overall psychomotor retardation/intellectual disability. We found that 18 patients (26.5%) presented alterations accounting for these symptoms. This percentage is similar to that from other series.[19,20]

In conclusion, this 20-year study reflects that paediatric neurology care strives to adapt to the continuous technical, scientific, and social advances in the field.

Conflicts of interest

The authors have no conflicts of interest to declare.

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