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ORIGINAL ARTICLE

Hospital care of patients with chronic pathology

Atención hospitalaria de pacientes con patología crónica

Pablo Gómez Garrido^a, María Suárez-Bustamante Huélamo^{b,c}, Enrique Villalobos Pinto^b, Azucena Retuerta Oliva^b, Dorleta López de Suso Martínez de Aguirre^b, Raquel Jiménez García^b

^aServicio de Pediatría, Hospital Universitario Severo Ochoa. Madrid, España

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What do we know about the subject matter of this study?

There is an increase in the prevalence of children with chronic and complex pathology. These patients have a higher number of admissions, longer stays, and require more healthcare resources, which generate high economic costs.

What does this study contribute to what is already known?

Our study describes neurological pathology as the main condition among children with chronic and complex pathology. In addition, it shows that patients with three or more chronic conditions and those with technological support are more frequently hospitalized.

Abstract

Advances in medical care have increased the survival of children with complex chronic pathology (CCP). **Objective**: to analyze the epidemiological and clinical characteristics of a cohort of children with CCP. Patients and Method: retrospective descriptive study performed in a tertiary hospital between June 2017 and June 2020, which included patients with CCP criteria. Epidemiological, clinical, admissions, and services involved data were collected and analyzed. Statistical analysis was performed using SPSS v22.0 software. Results: 323 patients (mean age 7 years) were included. 93.1% had a multisystem disease, with neurological (87.3%) and gastrointestinal (34.1%) as the most frequent chronic conditions. 39.9% were technology dependent. The main diagnoses were Infantile Cerebral Palsy (23.5%) and Epileptic Encephalopathy (13.9%). Each patient was in follow-up by 5 specialists on average. Of the patients, 85.1% were admitted at some time, with a total of 739 admissions. The mean length of stay was 8.7 days. Technology-dependent patients accounted for 54.7% of hospitalizations. The reasons for admission were acute illness (64.3%), surgery (20.3%), and diagnostic procedure (15%). ICU was required in 23.1%. 62 admissions were partially carried out by the Home Hospitalization Unit. Conclusions: Children with CCP require an increased number of admissions and multiple specialists. The implementation of specialized referral units may be useful to improve their care.

Keywords:

Pediatric Hospital, Multiple Chronic Conditions, Biomedical Technology, Home Care Services, Hospital-Based, Cerebral Palsy

Correspondence: Pablo Gómez Garrido paybolgg@gmail.com / pggarrido@salud.madrid.org Edited by: Pablo Cruces Romero

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^bServicio de Pediatría, Hospital Infantil Universitario Niño Jesús. Madrid, España

cResidente.

Introduction

Recent advances and improvements in pediatric care have led to reduced infant mortality and increased survival of children with serious illnesses, causing an increase in the prevalence of children with chronic pathology, with increased fragilty and medical complexity¹⁻⁵.

Children with special health care needs (CSHCN) are those who present or have a bigger risk to present a chronic physical, developmental, behavioral, or emotional pathology, and who therefore have a higher consumption of health care resources than the general pediatric population^{6,7}. Within this group are medically complex children (MCC) or children with complex chronic conditions (CCC). The most widely agreed definition of these children with CCCs refers to those patients with a medical condition that can reasonably be expected to last at least 12 months (unless death occurs) and involves different systems, usually more than two^{8,9,10}. The ICD-10 coding system expanded the definition to include patients with chronic pathology from the neonatal period, technology-dependent children daily, and organ transplant recipients10.

These patients require a higher number of admissions, preferably in tertiary hospitals, either on the ward or in intensive care units (ICU), with longer stays, more resource consumption and need for services and specialists^{4,10,11,12,13}. In addition, studies in the United States have shown that, although they account for 13-18% of all children seen, they may be responsible for 80% of the cost of child health care¹⁴. On the other hand, when they reach adulthood, these patients continue to require medical attention and a transition from pediatrics to internist care becomes advisable⁴.

As a result of the growing need for a comprehensive and coordinated assessment of these patients, specialized CCC units have been formed. There is already extensive literature that supports the significant improvement in medical care in different areas, highlighting a positive perception in patients, families, and health professionals^{10,15,16}; in addition to significantly reducing total medical costs.

The objective of this study is to analyze the epidemiological and clinical characteristics of children who meet CCC criteria and who are in follow-up at the *Hospital Infantil Universitario Niño Jesús de Madrid* (Spain), as well as the services involved in their follow-up, and the hospital admissions produced.

Patients and Method

The study was carried out at the *Hospital Infantil Universitario Niño Jesús de Madrid* (Spain), a tertiary-

level hospital that is the highest level of complexity according to the Spanish classification, providing care to up to 18 years of age. The center is located in the Community of Madrid, a region with a population of 6,736,407 inhabitants, including 1,354,727 children under 18 years of age. It has 180 basic care beds belonging to medical and surgical services, and 16 general pediatric intensive care beds (ICU). The hospital does not have a Neonatology service but attends newborns once they are discharged after 48 hours of life.

The services correspond to different medical and surgical specialties, one of them being the General Pediatrics unit. This service includes five sections: conventional hospitalization of acute patients, hospitalization of acute patients at home (UHAD), social pediatrics, adolescent pediatrics, and outpatient consultation of general pediatrics. The objective of the UHAD is to continue or initiate the admission of certain patients who meet a series of requirements of medical stability, geographic location, and family training at home; with daily monitoring by medical and nursing staff, improving recovery from the disease and greater compliance and family involvement in the care of the patient. The general pediatrics office attends to children with different pathologies and complexity, who require resources that cannot be managed directly by Primary Care.

Our study included those children with CCC treated in the General Pediatrics Service between June 10, 2017, and June 10, 2020, during hospital admission or consultation. During the study time, 19,820 hospital admissions were recorded, of which 5,713 were scheduled and 14,107 were due to urgent pathology. Of these, 5,001 corresponded to the General Pediatrics Section. Likewise, during this time, a total of 438,829 consultations were made, of which 13,621 were carried out in General Pediatrics.

Patients were selected assuming the circumstances of chronicity and complexity based on the diagnosis or base diagnoses recorded. The criterion for being categorized as CCC was to meet at least one of these two conditions: (a) severe multisystem disease: the presence of 2 or more complex health conditions, of chronic evolution or expected to last for a prolonged period (> 2 months), or (b) presence of a complex health condition with dependence on technological support (auxiliary medical-technology devices used daily) and/ or need for special care in the hospital or at home that is essential to prevent the patient's deterioration. Given their special nature, oncologic patients were excluded.

The clinical histories were reviewed in the hospital's computer program (HCIS), collecting and analyzing the epidemiological and clinical data of each patient, as well as the services involved in their follow-up and the main characteristics of hospital admissions such as age,

reason for hospitalization, service in charge, duration, diagnosis at discharge, complications, and need for ICU admission. With the data recorded, we compared the different variables between patients who had 3 or more chronic conditions with respect to those with less than 3, and between technology-dependent and non-technology-dependent patients.

Statistical analysis was performed with the IBM SPSS Statistics 23.0 software. The project was approved by the Clinical Research Ethics Committee of the Hospital, and with the consent of the relatives of the patients involved.

Results

Epidemiological data

We included 323 patients who met the inclusion criteria, of whom 54.8% were male (Table 1). The median age was 7 ± 5 years (IQR 7.1). The referral hospital was the *Hospital Niño Jesús* for 80.5% of the patients, while 63 (19.5%) were outpatients (mainly seen in other hospitals).

Clinical data

The criterion for inclusion as children with CCC was to present severe multisystem disease in 93.1% of the cases. Of these, 129 patients (39.9%) needed at least one technological support device (Figure 1). The most frequently observed chronic condition was neurologic (87.3%), gastrointestinal (54.5%), endocrinologic (34.1%), and respiratory (32.3%) pathology. 271 patients (83.9%) had a disease diagnosed at birth. The main underlying pathologies (Table 1) were infantile cerebral palsy (CP) (23.5%) and developmental and epileptic encephalopathy (DEE) (13.9%).

Follow-up

The main services involved in outpatient follow-up were: Neuropediatrics 52% (168), General Pediatrics 44.6% (144), Gastroenterology and Nutrition 42.7% (138), Rehabilitation 42.4% (137), and Orthopedic

Surgery and Traumatology (OST) 36.8% (119). The median number of services involved per patient was 5 (IQR 4). 53.2% of children were followed by 5 or more different services, and the median number of services was higher in patients with 3 or more chronic conditions (Table 2).

Admissions

During the study time, 739 admissions were recorded at the *Hospital Niño Jesús* (3.7% of total hospitalizations). Of the total admissions (404), 54.7% corresponded to patients requiring technological support. The mean length of stay was 8.7 days (range 1 - 174). The mean age at admission was 5 ± 4 years. There were no differences by sex. Among the baseline diagnoses, 23.5% of the admitted patients had CP, 22.9% had DEE, and 10.9% had Down syndrome.

60.1% of the patients were admitted from the emergency department, 20.3% were admitted for scheduled surgery, and 15% for another type of procedure or diagnostic test. The main reason for admission was an acute pathology (64.3%), with neurological causes in 42% of cases (320 admissions), infectious in 41.6% (307), respiratory in 29.5% (218), and gastrointestinal in 16.3% (123). Figure 2 shows the main discharge diagnoses.

General pediatrics accounted for 41.5% of admissions (accounting for 6.1% of admissions to this service), Neuropediatrics for 18.1%, and surgical services for 22.3%, mainly OST (8.3%). On 171 occasions (23.1%), the patient required ICU, with a mean stay of 7.5 days (range 1 - 168). The percentage of ICU hospitalization was higher in patients with 3 or more chronic conditions (25.1%) and technology-dependent patients (26.1%) compared with patients with less than 3 chronic conditions (20.9%) (Table 2) and non-technology-dependent (19.3%) (Table 3).

In 2019, an individualized assessment of hospitalizations showed a high need for complementary tests among admitted children with CCC (blood tests 75%, microbiological studies 68%, chest X-ray 55%), as well as treatments (antibiotics 75%, oxygen therapy 65.5%,

		DIAGNOSIS				
		Cerebral Palsy (CP)	Development and Epileptic Encephalopathy (DEE)	Down syndrome	Other diagnoses	
Sex	Male	40	22	25	90	177
	Female	36	23	10	77	146
Age (mean)		9.7 ± 5.8	7.2 ± 5	4.6 ± 3.7	6.29 ± 5.1	7 ± 5.1
Total		76	45	35	167	323

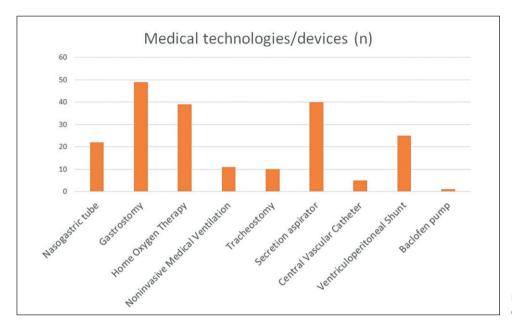


Figure 1. Medical technologies/devices (number of patients)

Variables	3 or more chronic conditions	Less than 3 chronic con- ditions	p value
n (%)	153 (47.3%)	170 (52.7%)	
Male sex	85 (55.5%)	92 (54.1%)	0.795
Number of services involved in follow-up per patient (mean)	5.81 (rango 0-11)	4.76 (rango 0-13)	< 0.01*
1 or more admissions	131 (85.6%)	144 (84.7%)	0.039*
Number of admissions (mean)	2.86 (rango 0-29)	1.94 (rango 0-11)	< 0.01*
Mean length of stay (days)	9.1 (rango 1-173)	8.2 (rango 1-136)	0.607
ICU hospitalization (admissions)	98 (25.6%)	73 (20.9%)	0.031*
Mean length of stay in ICU (days)	7.7 (rango 1-53)	7.3 (rango 1-157)	0.967

anticonvulsants 44%), and referrals to other services (60.2%).

The Acute Hospitalization at Home Unit (UHAD) started its activity in November 2018 (during the study period). A total of 62 admissions were recorded (15.7% of hospitalizations since that date), with a mean hospitalization at the home of 5.8 ± 4.8 days (range 1 - 33). Finally, 4 deaths were recorded during the period studied (1.2% of the sample), all of which required the use of appropriate therapeutic measures.

Discussion

Tertiary pediatric hospitals are experiencing an increase in the number of patients classifiable as

CCC^{1,4,5,17}. The *Hospital Niño Jesús* is no exception, probably because it is a reference center for subspecialties such as neuropediatrics. However, although there is a consensus definition, comparisons between hospitals are difficult because the criteria for defining these patients differ according to the study^{4,5,16}.

Before this work, few articles had been published in Spanish language on CCC. In Chile, Flores et al⁴ compared the main hospitalization data between children and youth with special health care needs (CYSHCN) and the rest of the patients (NON-CYSHCN). In Brazil, Moura EC et al were the first to measure national CCC hospitalization data (331 per 100,000 inhabitants)⁵. In Spain, the *Hospital Universitario La Paz* was the first in Madrid to create a CCC Unit. It reported having cared for 1027 patients between 2008 and 2016¹⁸. Later,

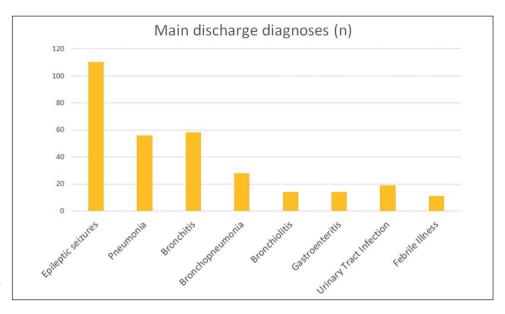


Figure 2. Main discharge diagnosis (number of patients)

Variables	Need of medical tech- nologies	No need of medical tech- nologies	p value
n (%)	129 (39.9%)	194 (60.1%)	
Male sex	67 (51.9%)	110 (56.7%)	0.40
Number of services involved in follow-up per patient (mean)	5.28 (rango 0-11)	5.24 (rango 0-13)	0.89
1 or more admissions	120 (93.1%)	155 (79.9%)	< 0.01*
Number of admissions (mean)	3.25 (0-11)	1.94 (0-29)	< 0.01*
Mean length of stay (days)	8.8 (rango 1-174)	8.5 (rango 1-137)	0.728
ICU hospitalization (admissions)	109 (26.1%)	62 (19.3%)	0.031*
Mean length of stay in ICU (days)	7.1 (rango 1-158)	8.4 (rango 1-53)	0.55

Sánchez-Penela et al. analyzed admissions to the General Pediatrics ward of the *Hospital Sant Joan de Déu* in Barcelona between December 2016 and November 2017, observing 14.4% of CCC¹⁹.

Both in the previously reviewed studies^{4,5,18} and in ours, the most frequently observed chronic condition is neurological involvement. Climent et al.¹⁸ note that other chronic conditions, mainly gastroenterological and respiratory, often present as comorbidities of the former. In our sample, the most repeated baseline diagnoses were ICP and Epileptic Encephalopathy, compatible entities that are usually the result of Hypoxic-Ischemic Encephalopathy (HIE) in the neonatal period. In addition, despite being a small sample, the percentage of males affected by ICP is higher, in agreement with previous literature^{4,5,20} (Table 1). The third most frequent underlying diagnosis is Down syndrome

(10.8%), for which there is a specialized consultation unit at the *Hospital Niño Jesús*, and which presents great variability in the clinical manifestations and chronic conditions generated. Comparing our data, 39.9% of the patients required technological support, a lower percentage than that reported by Climent et al (69.54%)18 or Sánchez-Penela et al (44.7%)¹⁹.

The management of these patients is usually multidisciplinary. Of our children, 53% were followed by 5 or more specialties (Table 2). This highlights the need to create coordination units specialized in the care of children with CCC. There is already a large literature on this subject in English^{1,2,5,10,15,21,22,23} and in Spanish^{4,16,18,24}. In September 2020, the *Hospital Niño Jesús* inaugurated a Chronic Pathology and Complexity Unit. The high level of parental satisfaction with these units has been previously demonstrated^{15,25}.

Our study included 739 admissions over 3 years. The percentage of admissions corresponding to CCC is probably higher than that recorded (3.7%) since only patients treated at some time in general pediatrics were included. Flores et al recorded 183 hospitalizations in only 3 months⁴ and Sanchez-Penela et al reported 207 admissions of CCC during one year¹⁹, although their data only referred to the General Pediatrics service. It is well known that children with CCC have a higher number of admissions than other children^{12,26,27} and that these tend to be longer and require more resources^{11,24}. In the study by Flores et al, 60.8% of admissions corresponded to patients categorized as CYSHCN, and 19.9% to the CYSHCN-3 group (followed by 3 or more health professionals)4. A study by Pérez-Moreno et al. analyzed all pediatric admissions to the Hospital Gregorio Marañón in Madrid and established that chronicity was the main risk factor for admission to Pediatrics²⁸.

It would also be logical to think that patients with a greater number of chronic conditions or requiring technical support would have an even higher number of admissions and that these would be more serious. In our analysis, we detected statistically significant differences in the percentage of hospitalization and the number of admissions both in patients with 3 or more chronic conditions compared with the rest of the patients (Table 2) and in those with technological support (Table 3) compared with those without it. These data complement those of Flores et al.4, which showed that the most severe chronic patients (CYSHCN-3) had 1.99 times the relative risk of prolonged hospitalization. The mean length of stay of admissions in our sample is prolonged (8.7 days). However, this average could be decreased due to the high percentage of patients hospitalized in a short period only for a single procedure or diagnostic test (15%).

This work does not include a socioeconomic analysis, which is present in other articles¹⁴. However, the analysis of the 2019 admissions showed a high proportion of patients requiring complementary tests, respiratory support, antibiotics, antiepileptic treatments, and the involvement of other services.

Also striking is the percentage of hospitalized patients with neurological pathology, particularly epileptic encephalopathy (22.9% of admissions, with only 13.9% being children). A total of 14.9% of admissions were due to the onset or poor control of epileptic seizures (Figure 2). However, as in the rest of the children, infectious and respiratory causes are the other main causes of hospitalization, coinciding with the studies of Sánchez-Penela et al¹⁹ and Flores et al⁴. Other frequent diagnoses are pneumonia, bronchitis, bronchiolitis, bronchopneumonia, and bronchospasm. Patients with neurological involvement have greater difficulty

in eliminating secretions, increasing the risk of bronchospasm¹⁰.

A high number of hospitalizations are due to surgery (20.3%) and procedures or diagnostic tests (15%). Children with ICP require frequent admissions for spasticity-related management or surgeries, either for relief (peripheral tenotomies and botox injections) or for after-effects (osteotomies or scoliosis surgery). Other reasons for admission are the study or treatment of epilepsy (video-electroencephalogram, establishment of ketogenic diet), and the initiation or modification of enteral support. Our figure for gastrostomy carriers (15.2%) is lower than that of other studies 12,18,19.

We can infer that CCC admissions tend to be more severe. In our sample, there was a high percentage of admissions to the ICU (23.1%), which was also higher in technology-dependent patients (26.1%) (Table 3) and with 3 or more chronic conditions (25.1%) (Table 2); with similar lengths of stay. Flores et al. have already reported a higher relative risk of admission to the ICU (1.58 times more than non-chronic patients)⁴. In general, ICU admissions of children with CCC are common^{4,13,18} even when their condition is not so severe, possibly due to the lack of specialized hospital units with specifically trained personnel. Climent et al. inferred that the high ratio of patients per physician and nurse does not allow adequate care for these children¹⁸.

Finally, we emphasize the usefulness of the Acute Hospitalization at Home Unit (UHAD), which, although it was theoretically created to care for the acute patient, was used by CCC on numerous occasions (15.7% of admissions since its opening). From our point of view, CCC home care should be contemplated for two reasons: because these patients suffer acute processes that require more frequent hospitalizations than the rest and because their parents are usually trained to perform medical care, especially when they need technological support or special attention. This would avoid problems derived from long hospital stays15,25 such as the risk of nosocomial infections, and would facilitate family reconciliation. There is already literature that supports this from a technical²⁹ and ethical perspective¹⁶.

We believe that our study is relevant, because there are still few similar publications in Spanish, particularly with such a large sample size (323 patients and 739 admissions), and also because it incorporates an analysis of admissions with a comparison between the most and least severe patients, and between technology-dependent patients and non-technology-dependent patients. Till the date, only Flores et al. and Sánchez-Penela et al. had published data on this subject in Spanish^{4,19} with other analyses in English^{10,11,11,12,26}.

The main weaknesses of this study are its retrospective design, the great heterogeneity of diagnosis, origin,

and management of the patients included, and the impossibility of registering all CCC under follow-up in the hospital, which makes it difficult to draw generalized conclusions.

Conclusions

According to the literature, there is a current increase in the number of children with CCC. The results of the study show that most of our patients had a neurological pathology, a possible conditioning factor for the rest; and that patients with more than 3 chronic conditions and those requiring technical assistance need more admissions than the others.

Given this circumstance, and in agreement with other authors, we consider the creation of reference units for the management of children with CCC to be positive, following the example of the existing ones. The coordination of these units with home hospitalization units could be useful and safe if there is adequate medical supervision and family training.

Ethical Responsibilities

Human Beings and animals protection: Disclosure

the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

Financial Disclosure

Authors state that no economic support has been associated with the present study.

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