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ORIGINAL ARTICLE

How can we improve the quality of health care in hospital attendance of medically complex children?

¿Cómo podemos mejorar la calidad de la atención hospitalaria de los pacientes crónicos complejos en pediatría?

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

Hospital care of children with complex chronic disease (CCD) is increasing. Its real prevalence is unknown due to a lack of unification of identification criteria. Also, there are few studies proposing strategies to improve the quality of care.

What does this study contribute to what is already known?

This study retrospectively analyzes the admissions and outpatient follow-up of children with CCD in a Spanish tertiary hospital over the last 5 years. It highlights a high annual frequency of outpatient visits, mainly in younger children, with a higher number of admissions and a lack of follow-up by the link nurse. Our strategy to improve the quality of care is the creation of multidisciplinary monographic consultations focused on the patients and their needs.

Abstract

Hospital care of medically complex children (MCC) is increasing, although its real prevalence in Spain is unknown. **Objective:** to analyze hospital admissions and outpatient follow-up of MCC in order to identify strategies to improve the quality of care of MCC. **Patients and Method:** An analytical, observational, and retrospective study was carried out. We included MCC who were admitted to Pediatric Hospitalization in the last 5 years, in a tertiary hospital without a specific unit for MCC. Clinical data related to their underlying pathology, outpatient visits, and hospital admissions were collected. A multivariate study was carried out to describe risk factors of the need for technological support and to predict prolonged admissions and the hospital consultation rate. **Results:** 99 MCC (55.6% males) aged 3.9 (2-8) years were included. 41.4% of MCC required technological support at home and presented the highest number of comorbidities, hospital admissions, and care by different specialists ($p < 0.01$). Older MCC ($p < 0.01$) with underlying digestive disease ($p < 0.04$) and

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respiratory comorbidity ($p < 0.04$) presented a longer mean hospital stays. Younger patients with more admissions, longer average stay, and a lack of follow-up by the link nurse were associated with a greater number of annual consultations ($p < 0.05$). **Conclusions:** MCC require a high number of annual consultations and have long hospital stays. The creation of specialized consultations for MCC, multidisciplinary care, and the participation of the link nurse are strategies to improve the quality of care for MCC in hospitals without specific MCC units.

Introduction

The improvement of pediatric care has led to a decrease in infant mortality and, therefore, an increase in the survival of children with severe complex pathology[1-3]. Chronicity in pediatrics generally includes very complex diseases with a low prevalence compared with the general population (< 1%)[4]. In spite of their low prevalence, they account forone-third of pediatric healthcare expenditure[5], generally due to a high number of hospitalizations with prolonged stays or the need for admission to Pediatric Intensive Care Units (PICU) and the high technological dependence and frequent multidisciplinary care[6-13]. Unlike what happens with adult chronic patients, the real prevalence of pediatric chronic patients in Spain is unknown, mainly due to the lack of identification criteria, the lack of specific protocols, the fact that most are treated in tertiary-level hospitals and that some patients come from other autonomous communities[14,15].

A recent study carried out in Barcelona shows a prevalence of 14.4%, higher than in previous studies, perhaps due to the existence of a specialized chronic care unit.

The most commonly used definition of a child with complex chronic disease (CCD) is "*a child with a serious medical condition that is expected to affect for a long period (at least 12 months or less in the case of death) and affects different organs or only one, but severe enough to require specialized pediatric care and long periods of hospitalization in a tertiary healthcare center*"[17-19]. Therefore, they are patients with functional limitations that may require the use of technology and high utilization of healthcare resources. Children with CCD are those who require the most attention within the so-called "Children with Special Health Care Needs", which encompasses a broad group of patients that are at a higher risk of presenting chronic physical, developmental, behavioral, or emotional pathology[19,20].

Pediatric hospitalists provides comprehensive, multidisciplinary, and coordinated care to all hospitalized children, including complex chronic patients who undoubtedly constitute an important challenge for the hospitalist[21,22]. Recently, in some countries such as the United States, specific programs and units have been developed for the care of these children with CCD[19-23]. In Spain, until 10 years ago, there were no specific plans for these patients, although in recent years hospitals such as *Hospital La Paz*[17] and the *Hospital San Juan de Dios*[16] have been pioneers in the development of these units.

Most studies on children with CCD analyze clinical characteristics, mortality, readmission rates, and economic cost. However, few studies analyze the role of comorbidities in the evolution of these patients, the risk factors for severity, and that propose strategies to improve the quality of inpatient and outpatient care.

The objectives of this study are to analyze the clinical characteristics, severity, and care needs of children with CCDs seen in the inpatient pediatric wards of our hospital, and to describe the risk factors for severity associated with their comorbidities. The analysis of these factors could serve as a basis for defining strategies to improve the quality of care for these patients.

Patients and Method

Observational, analytical, and retrospective study that included children with CCD admitted in the last 5 years (2016-2021) in pediatric hospital medicine wards in a third-level pediatric hospital in Madrid (Spain) with 38 pediatric hospitalization beds and 1,500 admissions each year, without specific complex chronic unit. Medical records of those patients who met the inclusion criteria were reviewed. Inclusion criteria were all patients aged 0-16 years admitted to the hospital at some time in the 5 years described and who met the definition of children with CCD by Cohen et al.[5] Patients under preferential follow-up by specialties other than Med-Peds (cardiology, oncohematology, and nephrology) were excluded.

We collected demographic variables (age, sex, date of death), variables related to the main disease (time of evolution, type of disease), comorbidities (nutritional, orthopedic, respiratory, psychiatric), basic treatment, the need for technological support at home at the time of admission (home monitoring, gastrostomy, tracheostomy, tracheostomy, home oxygen therapy, mechanical ventilation, cerebrospinal fluid diversion, central catheter), and hospital care (specialists in follow-up, number of visits, emergency care, admissions to the internal medicine ward and PICU up to the time of the study, and support required during admissions).

The characteristics of the patients and their admissions from birth to the time of the study were analyzed. The underlying disease is defined as the one that triggers all comorbidities over time. Comorbidity is defined as the presence of two or more diseases or disorders at the same time in the same person with a higher-than-expected frequency[23]. Comorbidities occur because of the main underlying disease.

Statistical analysis

Statistical analysis was performed using the SPSS version 25.0 and the R statistical software Version 3.5.1. Quantitative variables were expressed as median and interquartile range and qualitative variables were expressed as percentages. The Fisher test was used to compare qualitative variables and the Mann-Whitney U test and the Kruskal-Wallis test were used for the quantitative ones.

Logistic regression model was constructed to analyze the factors that could be related to the need for technological support in these patients. In this model,the covariables analyzed were those that were statistically significant or close to statistical significance ($p < 0.2$) in the bivariate study, as well as those that were clinically relevant. The results were expressed in the logistic regression model as OR and 95% CI.

To evaluate the duration of admissions, a linear regression model was constructed and those variables with $p < 0.2$ in the bivariate analysis or with clinical significance were introduced into the models. A Poisson regression model was constructed to evaluate the number of visits. The results in the linear regression models were expressed as t and p values.

The Akaike information criterion (AIC) and the Bayesian information criterion (BIC) were used as selection and comparison criteria between the regression models. A $p < 0.05$ was considered statistically significant.

To ensure confidentiality, no data allowing patient identification were included. The study was approved by the Hospital Clinical Research Ethics Committee (Code 457/20).

Results

General characteristics

99 children with CCD (55.6% male) with a median age of 3.9 (2-8) years were included. The most frequent underlying disease was genetic (28.3%), followed by neonatal (27.3%), and neurological (23.2%). The overall death rate was 8.1%. The time of evolution of their chronic disease was very heterogeneous with a median of 3.5 (2-6.5) years. Children with CCD required pharmacological treatment with a median of 4.5 (2-7) drugs. Those children with neurological-based pathology had more psychiatric (82.6%), orthopedic, and nutritional comorbidities ($p < 0.01$). In those with pathology of neonatal origin, respiratory comorbidity predominated (92.6%) followed by nutritional comorbidity ($p < 0.01$). Figure 1 shows the rest of the clinical characteristics and comorbidities of the patients according to their underlying disease.

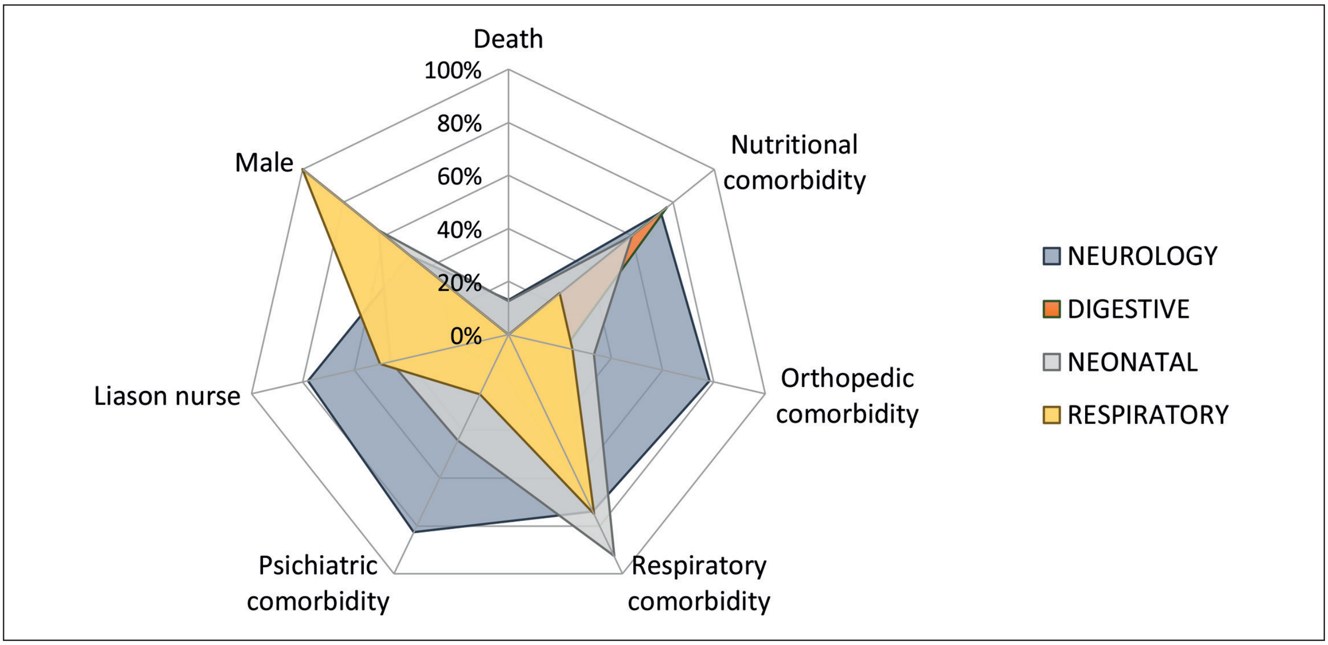


Figure 1. Clinical characteristics and comorbidity of Complex Chronic Disease (CCD) depending on main disease. Results are expressed in percentages.

Need for technological support

At the time of the study, 41.4% required technological support at home. The most frequent was enteral nutrition by gastrostomy (32.3%), mainly in neurological diseases (34.1%) or neonatal origin (34.1%). In the bivariate comparative study (table 1), patients requiring technological support were significantly older (4.5 vs. 3.6 years; p < 0.01), had a greater number of comorbidities (4 vs. 2.5; p < 0.01), mainly respiratory (90.2% vs. 56.9%; p < 0.01), digestive (80.5% vs. 51.7%; p < 0.01), or nutritional ones (78% vs. 48.3%; p < 0.01). These patients also presented a greater number of admissions (6 vs. 4; p < 0.01), greater need for specialist care (8 vs. 5.5; p < 0.01), higher number of drugs prescribed at baseline (6 vs. 3; p < 0.01), and greater follow-up by a link nurse hospital-primary care (83% vs. 28.1%; p < 0.01). In the multivariate analysis, children with CCD at higher risk of technology support were female [OR 4.16 (1.3-14); p = 0.01], with respiratory comorbidity [OR 7.5 (1.9-38); p < 0.01], higher number of PICU admissions [OR 1.62 (1.12-2.61); p = 0.01], and higher number of specialists in follow-up [OR 1.27 (1.01-1.3); p = 0.03] (table 3).

Comorbidities analysis

In the analysis by patient comorbidities, psychiatric comorbidity was most frequently observed in patients with neurological pathology (86%), followed by those with genetic (60.7%) and neonatal (44.4%) diseases. Respiratory comorbidity predominated significantly in neonatal patients (92.6%), followed by neurological patients (73.9%). Differences were also observed in digestive comorbidity, being more frequent in neu-

Table 1. Bivariate comparative study of CCD according to the need of technological support

	Without technological support N = 58	Without technological support N = 41	p
Age (years)	3,6 (2,1-5,5)	4,5 (2-9)	< 0,01
Male gender	63,8%	43,9%	0,06
Mortality	3,4%	15%	0,05
Main disease			
- Neurologic	15,2%	34,1%	0,07
- Digestive	12,1%	4,9%	
- Respiratory	5,3%	2,4%	
- Genetic	36,2%	17%	
- Neonatal	22,4%	34,1%	
- Others	8,8%	7,5%	
Digestive comorbidity	51,7%	80,5%	< 0,01
Nutritional comorbidity	48,3%	78%	< 0,01
Orthopaedic comorbidity	43,1%	58,5%	0,15
Respiratory comorbidity	56,9%	90,2%	< 0,01
Psychiatric comorbidity	50%	58,5%	0,42
Number of total comorbidities	2,5 (1,25-3,75)	4 (3-5)	< 0,01
Number of total medications	3 (1-5)	6 (3,7-9)	< 0,01
Number of subspecialist in care of a patient	5,5 (5-7)	8 (6-9)	< 0,01
Number of consultations	2,5 (1-5,3)	3,5 (1,7-6,4)	0,10
Number of hospital admissions	4 (2-7)	6 (3-11)	< 0,01
Number of PICU admissions	1 (0-1)	2 (1-2)	< 0,01
Average stay at admission	8,5 (5,5-15,5)	11 (6,5-24)	0,17
Follow up by link-nurse	28,1%	83%	< 0,01

U de Mann-Whitney. Quantitative variables were expressed as median and interquartile range and qualitative variables were expressed as percentages. Quantitative variables (age, number of comorbidities, number of medications, number of subspecialist in care of a patient, hospital admissions or average stay) where analysed by Mann-Whitney test. Qualitative variables (gender, main disease, comorbidities, follow up by link-nurse) where analysed by Fisher test. Abbreviations: Pediatric Intensive Care Units (PICU), complex chronic disease (CCD); p: statistical significance.

Table 2. A Poisson regression model constructed to evaluate the number of visits. The results in the linear regression models were expressed as t and p values

	Number of annual consultations/visits			
	Estimate Std	Std error	T value	P value
Age	-3,10	0,06	-5,29	< 0,01*
Number of admissions	3,67	0,28	13,18	< 0,01*
Average stay of admissions	5,11	0,05	9,75	< 0,01*
Number of comorbidities	8,11	1,58	5,10	< 0,01*
No link-nurse follow up	-3,27	4,33	-7,55	0,02*

R^2: 0.23. Complex Chronic Disease (CCD); p: statistical significance.

Table 3. A logistic regression model to evaluate the need of technological support.

	Need of technological support		
	OR	95% CI	p
Female gender	4,16	(1,3-14)	0,01
Number of specialist in care of patient	1,27	(1,02-1,60)	0,03
number of PICU admissions	1,62	(1,12-2,61)	0,01
Respiratory comorbidity	7,5	(1,9-38)	< 0,01
Number of medications prescribed at UMP	1,1	(0,81-1,3)	0,05

OR: odds ratio, CI: confidence interval, p: statistical significance, PICU: Pediatric Intensive Care Unit, UMP: Unique Model of Prescription (electronic prescription system of the Community of Madrid). Dependent variable: need of technological support. R^2: 0.49. AIC 106.6 (Akaike information criterion (AIC).

rological patients (73.9%), with neonatal pathology (70.4%), and with genetic diseases (57.1%). Finally, there was more orthopedic comorbidity in neurological patients (73.8%) and those with genetic diseases (53.6%) (figure 1).

In the multivariate study, the number of comorbidities was significantly associated with higher mortality as an independent risk factor (OR 10.1; 95%CI 2.33 - 89; R2: 0.41).

Analysis of hospital admissions

Patients were admitted a median of 2 (0.8-2.7) times per year, because of a worsening of their comorbidities as the most frequent cause, followed by planned admissions, and admissions for worsening of their underlying disease. The number of admissions for intercurrent digestive pathology was 2 (1-4) admissions with a maximum range of 9 admissions per year and, in the case of intercurrent respiratory pathology, it caused a median of 2 (1-5) admissions with a maximum range of 15 admissions per year. The maximum annual range of admissions was 9.2 and the number of previous admissions at the time of the study was 4 (2-8) with a maximum range of 35 previous admissions. Their median mean length of stay was 9.5 (6.2-20) days with a median number of prolonged admissions (>20 days of admission) of 1 (0-1). These patients were readmitted 1.5 times in the following 30 days, with 0.5% being early readmissions. During hospital admission, 90% required respiratory support and 66% required nutritional support. The mean annual number of PICU admissions was 0.5 (0.3-0.7). In the linear regression analysis, older children with CCD ($t = 2.65$; $p < 0.01$), with digestive base disease ($t=1.99$; $p<0.04$), and with respiratory comorbidity ($t = 2.03$; $p < 0.04$) had a longer mean length of stay during their admissions.

Analysis of outpatient follow-up

They attended 24 (15-38) annual visits in which a median of 6 (5-8) specialists were involved. Only 51% were followed up by the nurse hospital-primary care liaison. They required a median of 3 (1.5-5.75) ED visits per year. In the Poisson regression analysis, we included as covariates age, number of previous admissions, mean length of stay of these admissions, number of comorbidities of each patient, and follow-up by the link nurse. The dependent variable was the number of annual outpatient visits. In the final model, younger age ($t = -5.29$; $p < 0.01$), number of previous admissions ($t = 13.18$; $p < 0.01$), mean stay in admissions ($t = 9.75$; $p < 0.01$), number of comorbidities ($t = 5.10$; $p < 0.01$), and absence of follow-up by the link nurse ($t = -7.55$; $p < 0.01$) were identified as independent markers of increased need for outpatient follow-up. The Poisson regression model was significant with a pseudo-R2 of 0.23 (table 2).

Discussion

This study provides insight into the clinical characteristics of children with CCD, assesses their complexity based on the number of comorbidities and the need for technological support, and devises models of healthcare specifically designed for them. These models of healthcare could vary between different hospitals due to their level of sub-specialization. The analysis of this complexity could draw map of resources required by these patients and organize multidisciplinary consultations for the healthcare of these children.

One of the most relevant findings of this study is the high demand of chronic pediatric patients, both in hospitalization and in outpatient visits, which reflects a need of healthcare different from that of the rest of the pediatric population and which must be considered in order to improve the quality of care[14-16].

The need to attend 24 visits per year with an average of 6 different specialists makes it necessary to rethink a healthcare model centered on the children with CCD that improves the quality of care and better manages the healthcare resources aimed at these patients. This data also represent the family burden of having a child with CCD due to the multidisciplinary follow-up that should be focused on the patient and not on the disease.

The role of the pediatric hospitalist would be to coordinate the different specialist consultations so that the chronic patient would not have to attend an average of 24 visits per year, but monthly visits (according to their stability). In contrast, at this specific consult, the patient could be evaluated in one day by several specialists coordinated by the pediatric hospitalist. This pediatrician would be responsible for transmitting to each specialist the current state of health, the most relevant health needs affecting their quality of life, transmitting a single care plan, and agreeing on the medication of each specialist in order to avoid interactions. In addition to her/his role in the coordination of hospital specialists, the pediatric hospitalist would be responsible for transmitting these high-resolution consultations to the primary care pediatrician, who is responsible for the patient to ensure continuity of care and updating the patient's health problems.

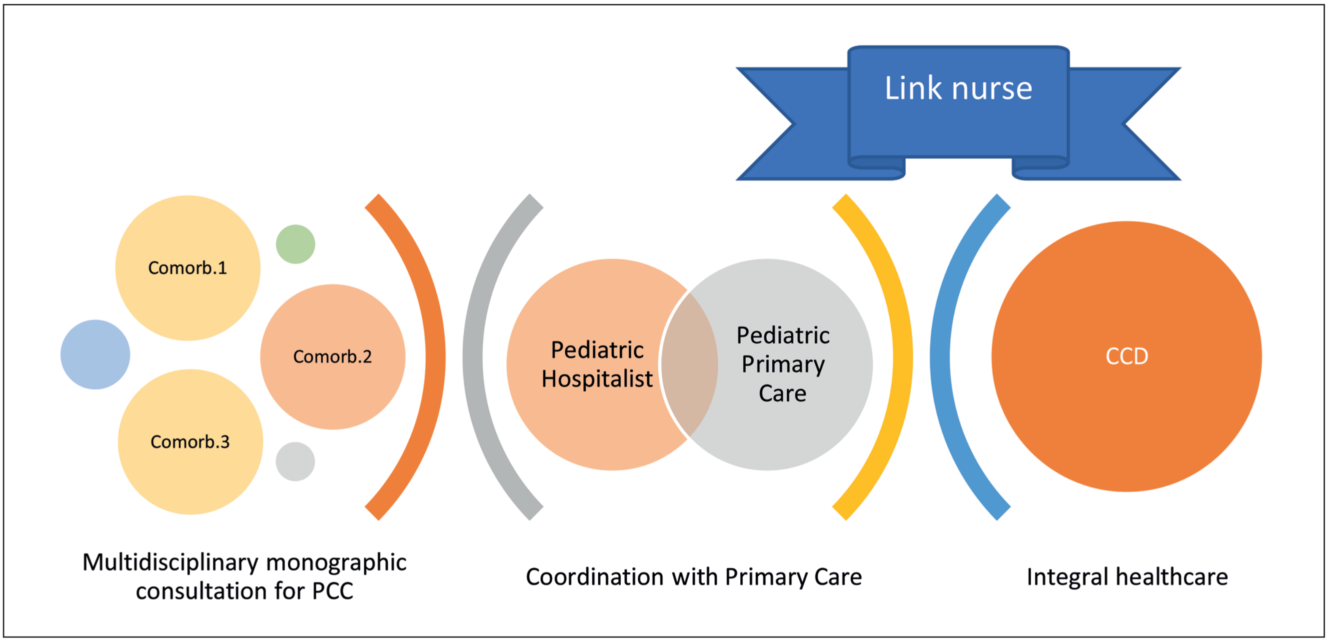
The analysis according to the underlying diseases allows us to visualize the needs of each patient according to their comorbidities. In our study, the main underlying diseases observed were genetic and neonatal, partly due to the third-level and highly complex Neonatology Unit. This contrasts with other hospitals, whose two main pathologies were neurological and gastrointestinal. The death rate of ~8% of children with CCD in the series was similar to that published in other studies[17]. The main comorbidities of the technology-dependent patients with CCD in this study were digestive/nutritional and respiratory. In the case of patients with predominantly neurological disease; the most frequent comorbidities were psychiatric, orthopedic, and digestive, In the case of patients with predominant neonatal pathology, the most frequent comorbidities were respiratory and digestive.

A good model of healthcare for these chronic patients would be the creation of multidisciplinary monographic consultations in which the pediatric hospitalist coordinates the other specialists to create an integrated care plan and provide a complete and structured report by comorbidities that includes all the patient's medication and the correct management of intercurrent events[21,24-33].

Monographic consultations are those that focus on the patients and their needs, not on their diagnoses. This would involve assessment in the same place and time by professionals from different pediatric specialties and coordinated by the pediatric hospitalist who will direct multidisciplinary care focused on the patient. Thus, the number of annual consultations could be reduced, improving the quality of life of the patient and their families[27], the quality of healthcare, and allowing savings in resources. These benefits will have to be contrasted in prospective studies after the implementation of the proposed measures. We, therefore, propose a multidisciplinary care model centered on the patient and coordinated by pediatric hospitalist and the link nurse. Pediatric hospitalist could alsocoordinate the different pediatric subspecialists on an individualized basis for each patient according to the predominant comorbidities in each patient.

The study of comorbidities in children with CCD is a very interesting approach since, in our study, the number of comorbidities was associated with mortality. The management of comorbidities in these patients is therefore of special importance and the focus should be on their early and multidisciplinary treatment. Previous studies carried out in adult chronic patients confirm a correlation between the different comorbidities of the patients and their quality of care[28]. This quality of care is affected when patients have unrelated comorbidities because they require more time for care, which may be insufficient and may lead to inadequate diagnosis and treatment[28]. We believe that the patients who would benefit most from monographic consultations would be younger children with CCD, those in need of technological support, and those who are frequently admitted and have longer admissions.

Third-level pediatric hospitals with chronic care units report an increase in their activity "beyond their possibilities"[17] given that they receive patients from other pediatric hospitals and other countries. It is



Graphic summary. Strategies to improve quality health care at hospital of CCD. Comorb: Comorbidity; CCD: Children with complex chronic disease.

therefore important to carry out an internal study of the patients with CCD in each hospital, to analyze their care needs and to organize and coordinate comprehensive patient care.

Another strategy that we believe would improve the quality of healthcare of children with CCD is the assessment of these patients by the link nurse. The role of the link nurse is key in pediatric chronic care and the coordination between primary and hospital care. In our study, those chronic patients without follow-up by the link nurse needed to attend a greater number of annual consultations. Therefore, the role of the link nurse is crucial to improve the coordination of healthcare, medication, and other important technological needs in the management of CCD at home.

It is important to highlight that, in our study, no patient was categorized from Primary Care as CCD which negatively influences the coordination between in-hospital and out-hospital care. This is mainly due to the lack of a global strategic plan for CCD care that would allow these patients to be identified from Primary Care, as has been managed in adult patients at Madrid since 2015[15]. Recent studies,[16] highlight the difficulty in adequately identifying children with CCD partly because it is a very heterogeneous population with a complexity that is difficult to code, sometimes using questionnaires to stratify the complexity of these patients[26].

It would be interesting for future studies to analyze the direct opinion of parents with standardized surveys to improve the quality of care during hospitalization. The characteristics of the patients were analyzed from birth to the time of the study, so the analysis of hospital admissions could present variability according to age, heterogeneity, and degree of stabilization of their diseases.In conclusion, children with CCD require a high number of annual consultations and have long hospital stays. There are risk factors that explain the complexity of these patients that explains the need of prevention strategies and a change on healthcare model according to their needs. The creation of specific monographic consultations and the correct care of their comorbidities through multidisciplinary care led and coordinated by the pediatric hospitalist and the link nurse seem to be the best short-term strategies to improve the quality of hospital care of patients with CCD (See graphic summary). A strategic plan for the care of chronicity in children coordinated between the different levels of heathcare is essential, similar to the strategic plans for chronicity in adults ¡ proposed by the Ministry of Health and the Health Departments of the different Autonomous Communities in our country.

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

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