

Hospital Inpatient Use in Mainland Portugal by Children with Complex Chronic Conditions (2011 – 2015)



Utilização do Internamento Hospitalar em Portugal Continental por Crianças com Doenças Crónicas Complexas (2011 – 2015)

Ana Forjaz LACERDA^{1,2}, Graça OLIVEIRA³, Cândida CANCELINHA^{1,4}, Sílvia LOPES^{5,6}
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ABSTRACT

Introduction: Due to epidemiological change, interest in complex chronic conditions has been increasing within the pediatric health system. As such, we aim to evaluate hospital inpatient care in the National Health Service (mainland Portugal) by pediatric patients (0 – 17 years) with complex chronic conditions.

Material and Methods: Observational longitudinal retrospective epidemiological study using anonymized administrative data. We selected hospitalizations within the pediatric age limit, 2011 – 2015; healthy newborns and radiotherapy outpatients were excluded. A descriptive analysis of the admissions with complex chronic conditions was analysed by number of complex chronic conditions categories and by complex chronic conditions categories. Non-parametric tests were applied to length of stay, expense, and mortality.

Results: Out of 419 927 admissions, 64 918 (15.5%) contained at least one complex chronic conditions code. These admissions due to complex chronic conditions represented 29.8% of hospital days, 39.4% of expense and 87.2% of deaths. Compared to those without complex chronic conditions, expense was double (median €1467 vs €745) and mortality 40 times higher (2.4% vs 0.06%). Of these, 46% were planned (no complex chronic conditions 23.2%); 64.8% occurred in group III – IV hospitals (no complex chronic conditions 27.1%). Malignant was the most frequent category (23.0%); neonatal had the highest median length of stay (12 days, 6 – 41), median expense (€3568,929 – 24 602), and number of deaths (43.5% of total).

Discussion: As in other developed countries where the number of pediatric admissions is decreasing, in mainland Portugal we found an increase in the proportion of complex chronic conditions admissions, which are longer, costlier and deadlier (trends intensified in the presence of two or more complex chronic conditions categories).

Conclusion: Complex chronic conditions are relevant in the activity and costs regarding pediatric hospitalizations in mainland Portugal. Recognizing this and integrating pediatric palliative care from the moment of diagnosis are essential to promote appropriate hospital use, through the development of effective and sustainable alternatives that meet the needs of children, families, and healthcare professionals.

Keywords: Child; Hospitalization; Needs Assessment; Palliative Care; Portugal

RESUMO

Introdução: Fruto da mudança epidemiológica, o interesse pelas doenças crónicas complexas no sistema de saúde pediátrico tem vindo a crescer. Assim, pretendemos avaliar a utilização do internamento hospitalar do Serviço Nacional de Saúde (Portugal Continental) por doentes pediátricos (0 – 17 anos) com doenças crónicas complexas.

Material e Métodos: Estudo epidemiológico observacional longitudinal retrospectivo (base de dados de morbilidade hospitalar anonimizada). Seleccionámos episódios de internamento de doentes pediátricos, entre 2011 – 2015; excluimos recém-nascidos saudáveis e radioterapia ambulatória. Análise descritiva dos episódios de internamento de doentes pediátricos com doenças crónicas complexas, caracterizados por número e categoria de doenças crónicas complexas. Foram aplicados testes não paramétricos à duração de internamento, despesa e mortalidade.

Resultados: Nos 419 927 episódios, constavam códigos de doenças crónicas complexas em 64 918 (15,5%). Estes episódios com doenças crónicas complexas representaram 29,8% dos dias de internamento, 39,4% da despesa e 87,2% dos óbitos. Custaram o dobro dos episódios sem doenças crónicas complexas (€1467 vs €745) e tiveram uma mortalidade 40 vezes superior (2,4% vs 0,06%). Do total, 46,0% foram programados (sem doenças crónicas complexas 23,2%); 64,8% ocorreram em hospitais grupo III – IV (sem doenças crónicas complexas 27,1%). Nos episódios com doenças crónicas complexas, a doença maligna foi a categoria mais frequente (23,0%); a maior demora mediana (12 dias, 6 – 41), despesa mediana (€3568,929 – 24 602) e mortalidade (13,4%) verificaram-se na categoria neonatais.

Discussão: Esta análise mostrou que, embora o número absoluto de internamentos de doentes pediátricos esteja a diminuir em Portugal Continental, à semelhança de outros países desenvolvidos, os internamentos com doenças crónicas complexas têm vindo a aumentar proporcionalmente, sendo mais prolongados, onerosos e com maior probabilidade de morte do que os episódios sem doenças crónicas complexas (tendências acentuadas quando constam duas ou mais doenças crónicas complexas).

Conclusão: As doenças crónicas complexas são relevantes na atividade e despesa do internamento hospitalar pediátrico em Portugal Continental. Este reconhecimento e a integração de cuidados paliativos pediátricos desde o diagnóstico são essenciais para adequar a

1. Observatório Português de Cuidados Paliativos. Instituto de Ciências da Saúde. Universidade Católica Portuguesa. Lisboa. Portugal.

2. Serviço de Pediatria. Instituto Português de Oncologia de Lisboa Francisco Gentil. Lisboa. Portugal.

3. Departamento de Pediatria. Hospital de Santa Maria. Centro Hospitalar Lisboa Norte. Lisboa. Portugal.

4. Serviço de Pediatria Médica. Departamento Pediátrico. Centro Hospitalar e Universitário de Coimbra. Coimbra. Portugal.

5. Departamento de Políticas e Gestão do Sistema de Saúde. Escola Nacional de Saúde Pública. Universidade NOVA de Lisboa. Lisboa. Portugal.

6. Centro de Investigação em Saúde Pública. Escola Nacional de Saúde Pública. Universidade NOVA de Lisboa. Lisboa. Portugal.

✉ Autor correspondente: Ana Forjaz Lacerda. alacerda@ipolisboa.min-saude.pt

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utilização do hospital, desenvolvendo alternativas efetivas e sustentáveis que vão ao encontro das necessidades das crianças, famílias e profissionais.

Palavras-chave: Criança; Cuidados Paliativos; Determinação de Necessidades de Cuidados de Saúde; Hospitalização; Portugal

INTRODUCTION

Over the past few years, there is a growing interest within healthcare systems on chronic conditions, as a result of an epidemiological change that occurred on the past few decades. Paediatrics is no exception, due to the increasing survival of newborn babies and children with complex health needs and conditions that previously followed a rapidly fatal course.^{1–4}

In addition, the current socioeconomic setting forced to reconsider the healthcare system which in the 21st century has to be rationalised, proactive rather than reactive and patient-oriented rather than disease-oriented or centred in the routines of professionals and healthcare institutions.^{5–7}

This renovation relates also to the expansion of palliative care and its scope, currently within its ‘third wave’, not restricted to the patient’s end-stage of illness,⁸ which has led in 2014 to the recommendation of the United Nations General Assembly on the full integration of palliative care in the healthcare systems of the Member States.⁹

Health needs assessment is one of the leading requirements for the equitable and sustainable service development.¹⁰ A classification aimed at analysing the prevalence of children presenting with complex conditions and in need for paediatric palliative care was developed — complex chronic conditions (CCC).¹¹ Used in different countries in studies of mortality,^{3,12–14} it also allowed for the identification of high healthcare utilisers.^{15–18} A coordinated health and psycho-social support is required from diagnosis, aimed both to the family and the community,⁶ one of the basic principles of paediatric palliative care.¹⁹ The need to draw boundaries between children with limiting or life-threatening diseases and children with disabilities is also crucial,^{20,21} leading to the subsequent recommendation for the organisation of equitable and sustainable services aimed at crossing these boundaries.^{4,20,21}

A recent warning sign for the modification of the Portuguese paediatric reality has occurred. The activity in paediatric palliative care was not officially recognised in Portugal until 2013.²² Since then, with the development of two working groups within the Portuguese Society of Paediatrics (*Sociedade Portuguesa de Pediatria*) and the Portuguese Association of Palliative Care (*Associação Portuguesa de Cuidados Paliativos*), the subject has gained an increasing visibility. The strategic implementation of paediatric palliative care teams and units was recommended by the report of the working group appointed by the Ministry of Health and published in 2015.²³ However, no study was ever carried out in Portugal as regards the frequency of children with palliative care needs, a priority that was already recognised in other countries.^{20,24,25}

This study was aimed at the evaluation of paediatric inpatient use by patients with CCC within the National Health Service (*Serviço Nacional de Saúde* [SNS]) in mainland

Portugal, as a starting point for a revision of the healthcare model.

MATERIAL AND METHODS

This was an epidemiological, observational, longitudinal and retrospective study aimed at the analysis of inpatient episodes related to paediatric patients with CCC within public hospitals in mainland Portugal²⁶ throughout a five-year period (1 Jan 2011 – 31 Dec 2015).

Complex chronic conditions

A classification developed in 2000 in the United States of America (USA) by Feudtner *et al.* was used in the study, according to the study’s aim, in which CCC was defined as “any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center”.¹¹

This is an easy-to-use, comprehensive and flexible classification based on codes of the *International Classification of Diseases* (ICD) and focused not only on the duration or severity of conditions, as well as on healthcare use. The list was recently updated and extended, including neonatal codes and other indicators of technology dependence or organ transplantation.¹⁶

In this most recent version, CCC are divided into ten categories: neurological & neuromuscular, cardiovascular, respiratory, renal & urological, gastrointestinal, haematological / immunological, metabolic, other congenital / genetic defect, malignancy and premature & neonatal. Two domains were also included — one regarding technology dependence and another regarding transplantation (separated from the remaining categories when not classified within one of those — children with 0 categories).

Data source

Data regarding inpatient episodes in mainland Portugal are routinely collected to the hospital morbidity database of the *Administração Central do Sistema de Saúde* (ACSS), from which anonymised data are released to the National School of Public Health (*Escola Nacional de Saúde Pública* [ENSP-NOVA]).

Information regarding patient’s demographic characteristics was obtained from the database (age, parish of residence), as well as data regarding admission and discharge date, admission type (urgent or elective), hospital, diagnosis and procedures [according to the *International Classification of Diseases* - 9th revision — Clinical Modifications (ICD-9-CM); maximum number of 59 and 51 per episode, respectively], DRG (Diagnosis Related Groups), length of

stay and discharge destination.

Study population

Inpatient episodes related to patients aged 0 to 17 years and 364 days were included in the study, considering the lowest value within the year of each episode.

Inpatient episodes related to liveborn infants (V30-V39 ICD-9-CM principal diagnosis codes) who were discharged alive and with ≤ 3 -day length of stay ($n = 270,572$), as well as episodes involving the use of radiation therapy as an outpatient (V580 ICD-9-CM principal diagnosis codes, length of stay of 0 and no ICD-9-CM codes required by the DRG ordinance to be considered as an outpatient episode, $n = 8,061$).

Definition of other variables

Whenever the 'parish of residence' variable had different values throughout the year, the value assigned to the earliest episode of the year was considered. The municipality of residence was based on the parish and was aggregated into 'place of residence' at the NUTS II level (Northern, Central, Lisbon Metropolitan Area, Alentejo, Algarve and Autonomous Regions).²⁷ Inpatient episodes in which the patient's place or residence was unavailable were excluded from the analysis (total: 1,897, 0.5%; patients with CCC: 645, 1.0%).

The classification of the 49 public (SNS) hospitals was based on the Ordinance no. 82/2014, under which institutions were classified in four groups, according to their area of influence and provided specialties: group I (lower complexity, in a direct area of influence), group II (intermediate complexity, in a direct and indirect area of influence), group III (higher complexity, in a direct and indirect area of influence) and group IV (specialised hospitals — Oncology, Rehabilitation and Mental Health). Some hospitals were excluded from the study due to not having been included in this Ordinance and these represented a residual number of episodes (four hospitals, 0.03% of the total inpatient episodes; two hospitals, 0.01% of the episodes related to patients with CCC).

The Ordinance that was applicable to the last year of the study (Ordinance no. 234/2015) has been used to estimate the cost associated with the episodes, based on the corresponding DRG weight.

In order to enhance the analysis and due to the fact that other authors have already described that the combination of CCC represents a higher complexity level of health-care,^{15,17,18} we decided in favour of considering two groups of patients (one of more than 2 CCC).

Approvals

Considering the study design and the release of anonymised data to the ENSP-NOVA for research, no approval by the Ethics Committee and/or the *Comissão Nacional de Proteção de Dados* was required.

Analysis

Paediatrics inpatient setting was considered in the first

part of the study. Clinical episodes were characterised according to the patient's place of residence, admission type and hospital group. Median test (length of stay and cost, non-normal distribution) and chi-square test (mortality) have been used to check whether or not there is a significant difference between inpatient episodes related to patients with vs. without CCC. A descriptive analysis of the annual trend of the frequency, length of stay, cost and mortality of inpatient episodes related to patients with CCC has been carried out (in absolute value and in percentage of total paediatrics inpatient episodes).

The characterisation of the episodes related to patients with CCC was analysed in the second part of the study, including its distribution by number of CCC and category, with a subsequent analysis of the annual absolute and relative frequencies for each of these groups, region of residence, type of admission and hospital group. This group of paediatric patients was compared to the remaining patients, as regards the length of stay and cost (median test) and mortality (chi-square test), in order to check the differences associated with the presence of two or more CCC.

Data were analysed with the use of SPSS v24[®] and Excel 2011[®] software.

RESULTS

A total number of 419,927 paediatric inpatient episodes were recorded throughout the five-year study period (Table 1). At least one CCC code was found in 64,918 inpatient episodes (15.5%). In mainland Portugal, the highest number of episodes related to patients with CCC was found in patients living in the northern region (23,194) and the lowest in the Algarve (2,839); however, the highest percentage of episodes related to patients with CCC was found in the Lisbon Metropolitan Area (18.7%) and the lowest in the central region (12.8%). Inpatient episodes related to patients living in the Autonomous Regions were only those in whom the transfer to more specialised hospitals in mainland Portugal was required and these were not representative of all inpatients. Almost half (46.0%) of the episodes related to patients with CCC were elective admissions (the double of the episodes related to patients without CCC, 23.2%) and mostly (64.8%) occurred within more specialised group III and IV hospitals (vs. 27.1% of the episodes related to patients without CCC). When compared to the episodes related to patients without CCC, those related to patients with CCC were significantly ($p < 0.01$) longer (median of 5 vs. 3 days) and involved higher costs (median of €1,467 vs. €745). A higher mortality has also been found (2.4% vs. 0.06%; $p < 0.01$).

A higher frequency of inpatient episodes involving transfer to other hospitals has also been found in episodes related to patients with CCC (6.1% vs. 2.1%).

An increasing percentage (from 14.9% to 16.1%) of inpatient episodes related to paediatric patients with CCC has been found between 2011 and 2015 (Fig. 1). Within this period, inpatient episodes related to patients with CCC corresponded on average to 29.8% of the length of stay,

Table 1 – Paediatric inpatient episodes related to patients with and without complex chronic conditions, mainland Portugal, 2011 – 2015

	Total	Without CCC		With CCC	
	n	n	n	Percentage from total	Percentage from the episodes related to patients with CCC
Total	419,927	355,009	64,918	15.5%	100.0%
Region of residence					
Alentejo	27,792	24,014	3,778	13.6%	5.8%
Algarve	20,899	18,060	2,839	13.6%	4.4%
Lisbon Metropolitan Area	110,933	90,215	20,718	18.7%	31.9%
Central region	99,124	86,449	12,675	12.8%	19.5%
Northern region	157,662	134,468	23,194	14.7%	35.7%
Autonomous Regions	1,620	551	1,069	66.0%	1.6%
Type of admission					
Urgent	307,828	272,742	35,086	11.4%	54.0%
Elective	112,099	82,267	29,832	26.6%	46.0%
Hospital group					
Group I	184,868	172,239	12,629	6.8%	19.5%
Group II	96,805	86,612	10,193	10.5%	15.7%
Group III	129,191	95,583	33,608	26.0%	51.8%
Group IV	8,951	468	8,483	94.8%	13.1%
Length of stay (days)					
Median (IQR)	4 (2 – 6)	3 (2 – 5)	5 (2 – 10)	—	—
Cost (€)					
Median (IQR)	811 (579 – 1297)	745 (575 – 1112)	1,467 (880 – 2,666)	—	—
Mortality	1,765	226	1,539	87.2%	2.4%

IQR: interquartile range; CCC: complex chronic conditions. The value of the first and the third quartile are shown in brackets. The disaggregated values of the episodes with unavailable patient's valid residence are not presented in the analysis by the region of residence (0.5% of the total; 1.0% of the episodes related to patients with CCC). Hospital groups defined according to the Ordinance no. 84/2014. The disaggregated values of the episodes related to hospitals with no classification regarding their type are not shown in the analysis by hospital group (0.03% of the total; 0.01% of the episodes related to patients with CCC). Estimated expenditure according to the Ordinance no. 234/2015.

39.4% of the cost and 87.2% of mortality. The representativeness of inpatient episodes related to patients with CCC has increased throughout the study period as regards the length of stay (from 28.0% to 30.4%) and cost (from 38.0% to 40.8%). An 86.5% mortality rate has been found in 2011 and 86.0% in 2015.

A trend towards the proportional value of CCC has been found, even though an absolute reduction in the frequency has been found in inpatient episodes related to patients with CCC over the study period (13,325 to 12,750), as well as regarding the length of stay (from around 141 thousand days to 131 thousand) and mortality (from 360 to 265) (Fig. 2). Costs stayed between 47.9 and 49.5 million euro.

Most inpatient episodes related to patients with CCC (51,301; 79.0%) presented within only one category (Fig. 3, Table 2). No CCC category codes and with only codes within the domains of technology dependence or transplantation (0 categories) were found in 1.1% of the episodes (715). Most of these episodes with 0 categories of CCC have occurred in patients living in the northern region (55.1%) and regarded elective admissions (61.3%).

A higher percentage of episodes has been found in hospitals from mainland Portugal, involving patients living in the Autonomous Regions when at least two categories of CCC were present, when compared to the presence of 1 category and 0 categories (2.3% vs. 1.5% and 0.8%) (Table 2).

Whenever two or more CCC categories were present, a

significantly higher median length of stay (7 days vs. 4 days and 4 days, $p < 0.01$) has been found, as well as regarding median costs (€2,058 vs. €1,344 and €1,573, $p < 0.01$) and the percentage of inpatients episodes related to deceased patients (4.7% vs. 1.8% and 0.0%, $p < 0.01$) (Table 2).

The presence of malignancy was predominant amongst the 10 CCC categories (Table 2), corresponding to 23.0% of the episodes, followed by neurological /neuromuscular disorders (17.6%), cardiovascular (15.4%), renal / urological (13.1%), haematological / immunological (12.4%), other congenital / genetic disorders (11.6%), gastrointestinal (9.9%), neonatal (7.7%), metabolic (7.3%) and respiratory (5.6%). A 100% rate has been exceeded by the sum of these percentages as more than one category could have been assigned to the same inpatient episode.

The regional distribution of the 10 CCC categories has followed a general pattern (slightly more than one third of the episodes were related to patients living in the northern region), except the categories regarding other congenital / genetic disorders (42.6% in the northern region), haematological / immunological (47.7% in the Lisbon Metropolitan Area) and metabolic (49.0% in the northern region).

Inpatient episodes related to patients with malignancy disorders corresponded mostly to elective admissions (69.1%). A higher percentage of urgent admissions (76.7%) has been found in inpatient episodes related to patients with neonatal disorders.

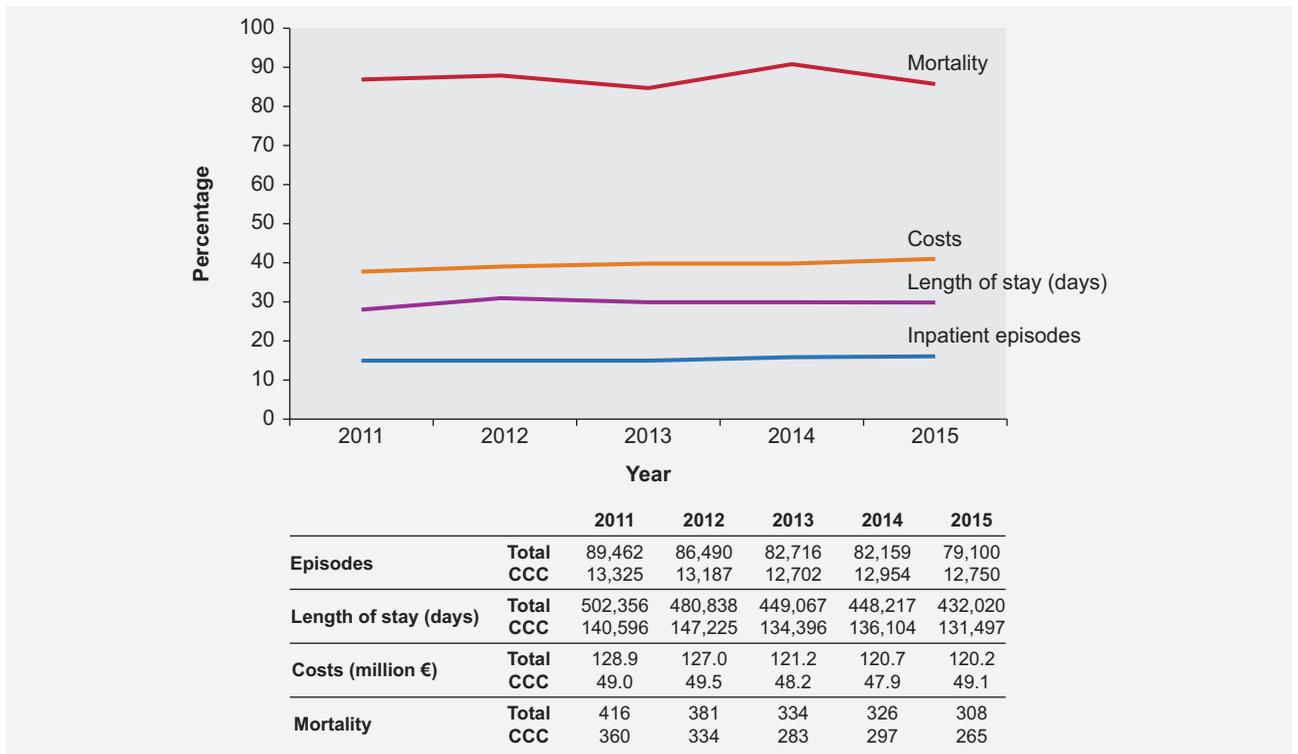


Figure 1 – Annual trend of the percentage of inpatient episodes, length of stay, cost and mortality related to patients with complex chronic conditions, mainland Portugal, 2011-2015

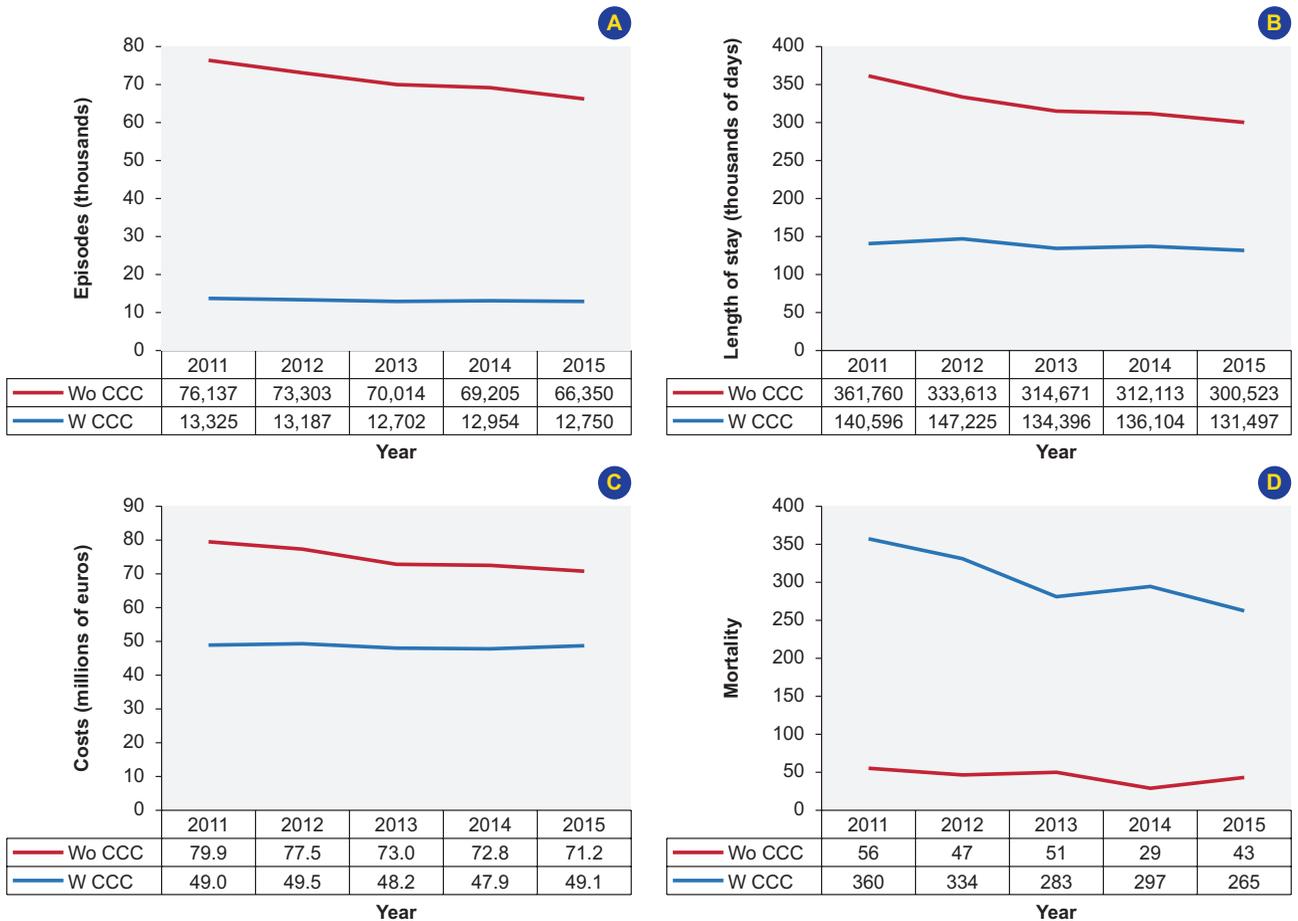


Figure 2 – Annual trend of paediatric inpatient episodes (A), length of stay (B), costs (C) and mortality (D) related to patients with and without complex chronic conditions, mainland Portugal, 2011-2015
 Wo CCC: without complex chronic conditions; W CCC: With complex chronic conditions

Table 2 – Paediatric inpatient episodes related to patients with complex chronic conditions, mainland Portugal, 2011 – 2015

	Number of categories			Categories											
	0	1	2+	Neurological / neuromuscular	Cardiovascular	Respiratory	Renal / urological	Gastrointestinal	Haematological / immunological	Metabolic	Other genetic / congenital disorders	Malignancy	Premature & Neonatal		
Total	715	51,301	12,902	11,410	10,023	3,651	8,532	6,420	8,037	4,752	7,504	14,908	4,994		
	n	n	n	n	n	n	n	n	n	n	n	n	n		
	%	%	%	%	%	%	%	%	%	%	%	%	%		
Region of residence															
Alejo	49	3,061	668	571	666	144	391	366	508	254	382	937	280		
	6.9%	2,244	5.2%	5.0%	6.6%	3.9%	4.6%	5.7%	6.3%	5.3%	5.1%	6.3%	5.6%		
	3.6%	4.4%	4.4%	5.3%	4.8%	5.0%	4.0%	4.9%	4.9%	6.6%	271	461	216		
	22.4%	16,467	32.1%	30.9%	33.5%	30.2%	30.5%	30.6%	38.33	22.4%	2,202	3,988	1,861		
Lisbon Metropolitan Area	160	32,117	4,091	3,524	4,782	1,103	2,606	1,967	3,833	1,065	2,202	3,988	1,861		
	22.4%	20,524	20.5%	20.1%	19.1%	21.4%	19.9%	21.0%	1,042	13.0%	1,360	3,024	20.3%		
Central	78	17,761	34.6%	37.4%	33.7%	33.7%	38.8%	35.9%	1,968	24.5%	2,327	49.0%	1,730		
Northern	394	788	1.5%	0.9%	1.6%	0.8%	1.7%	1.6%	167	2.1%	74	533	3.6%		
Autonomous Regions	6	27,611	53.8%	55.8%	51.2%	64.9%	53.9%	58.5%	5,290	65.8%	2,986	62.8%	3,829		
	0.8%	23,690	46.2%	44.2%	48.8%	35.1%	46.1%	41.5%	2,747	34.2%	1,766	37.2%	10,307		
	38.7%	46.2%	5.704	34.7%	4.888	1,282	3,933	2,662	2,747	34.2%	1,766	37.2%	10,307		
	61.3%	46.2%	5.704	34.7%	4.888	1,282	3,933	2,662	2,747	34.2%	1,766	37.2%	10,307		
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	61.3%	46.2%	5.704	34.7%	4.888	1,282	3,933	2,662	2,747	34.2%	1,766	37.2%	10,307		
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More than half (55.8%) of the episodes related to patients with malignancy disorders have been found in group IV hospitals while most of the episodes regarding the other CCC categories have occurred in group III hospitals, ranging between 42.4% (haematological / immunological) and 68.8% (gastrointestinal).

Longer hospital stay has been found in inpatient episodes related to patients with neonatal CCC categories (median: 12 days), while shorter stays have been found in metabolic and malignancy categories (median: 4 days).

Median costs have ranged between €968 (metabolic diseases) and €3,568 (neonatal), while higher than the median costs were related to malignancy (€2,655), cardiovascular and respiratory (€1,720) CCC categories.

Higher mortality rate has been found in neonatal (13.4%), respiratory (4.1%) and cardiovascular (3.3%) categories.

An increasing trend in the relative percentage of respiratory, other congenital /genetic disorders, neurological / neuromuscular, haematological / immunological, metabolic and gastrointestinal categories has been found between 2011 and 2015, while an opposite trend has been found regarding malignancy, cardiovascular, renal /urological and neonatal disorders (Fig. 3).

DISCUSSION

This was the first study regarding inpatient use of paediatric patients from mainland Portugal and one of the first international studies using the updated revision of CCC codes.¹⁶

This national database regarding the 2011-2015 hospital data has shown that, even though the absolute number

of admissions of paediatric patients has been reduced, the admissions of children with CCC have increased proportionally, have regarded longer episodes and involved higher costs and higher mortality than the remaining. Increasing differences were found whenever more than one CCC code has been recorded. A recent study on the short-term paediatric inpatient episodes (emergency department) in a national tertiary hospital had already shown that patients with a chronic condition, representing 19.9% of the episodes, remained longer in hospital and their transfer to a ward was more likely.²⁸

In this study, 15.5% of the episodes related to patients with CCC codes corresponded to 29.8% of the length of stay, 39.4% of costs and 87.2% of mortality. In a sample of North-American hospitals, CCC represented 10% of hospital admissions in 2006 and 25% of the length of stay, 40% of costs and 43% of mortality.¹⁵ An 11.6% rate of episodes with CCC has been found in the study in which the revision of the CCC classification was based on (USA, 2009 – 2010).¹⁶ The higher rate of episodes and mortality that was found in mainland Portugal could have been due to the lack of an alternative healthcare, namely at home and within the community.

An increasing weight of CCC in hospital resource use has also been described by other authors,^{15,17,18} which could have been due to multiple factors including the increasing survival of paediatric patients with CCC³ and increasing complexity throughout their growth.^{15,29} In addition, the number of episodes related to patients with CCC could increase due to the reduction in the length of stay, with interspersed periods of home-care¹⁷ leading to frequent readmissions in need for healthcare³⁰ and probably due to the absence of

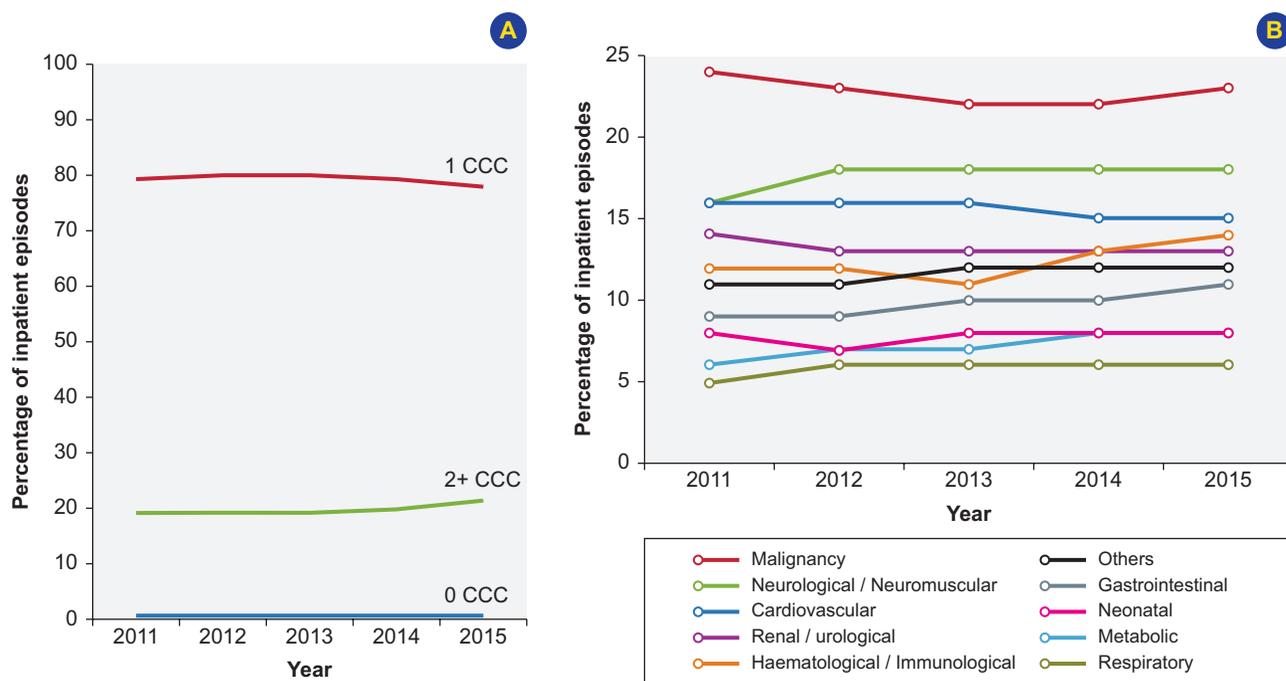


Figure 3 – Annual trend of inpatient episodes related to paediatric patients with complex chronic conditions, mainland Portugal, 2011-2015. (A) By number of categories of complex chronic conditions; (B) By categories of complex chronic conditions.

response outside a hospital.^{18,31} Also, the fragmentation and lack of coordination between healthcare providers within the healthcare system, more significant with the presence of technology dependency, are destabilising factors to patients and their families,³² leading to more frequent readmissions and longer stays than desirable.^{6,33}

In addition, healthcare of more frequent and less severe pathologies could have been displaced to outpatient clinics.^{15,29} In fact, the number and length of stay of episodes related to patient without CCC have been reduced in mainland Portugal throughout the study period.

Despite the highest absolute number of inpatient episodes related to patients with CCC has been recorded in the northern region, the highest rate of episodes with CCC has been found in the Lisbon Metropolitan Area. Most episodes related to other congenital / genetic and metabolic disorders, as well as those regarding 'technology dependence or transplantation' domains have occurred in patients living in the northern region, while almost half of the episodes related to haematological / immunological diseases have occurred in patients living in the Lisbon Metropolitan Area. These findings could have been due to the different regional prevalence of CCC or to a different availability of healthcare, namely for diagnosis or outpatient follow-up.

The need for transfer to specialised centres (as in case of malignancy and haematological / immunological disorders) is reflected by the fact that two thirds of the episodes regarding patients living in the Autonomous Regions were related to patients with CCC codes (and the highest percentage of episodes related to patients with two or more categories - 27.6%).

While most inpatient episodes related to patients with CCC have occurred in group III and IV hospitals (64.8%), almost half of the episodes related to patients without CCC (48.5%) have occurred in group I hospitals. This disparity is probably related to the different complexity between both clinical situations.

Malignancy is the predominant CCC in paediatric inpatient episodes, in contrast to the USA where cardiovascular and neurological / neuromuscular categories prevail.¹⁶ This could have been due to the promotion of outpatient and home support treatment and care to paediatric patients with cancer in this country (USA, 2003).³⁴

Also, an increasing rate of inpatient episodes, length of stay and cost have been found in the USA regarding all the categories of CCC except the haematological / immunological.¹⁵ This trend has not been evaluated in our study, due to the short time frame of the study. Its assessment in further studies will be relevant due to a conflicting evidence regarding the presence of less alternatives of healthcare outside the hospital for paediatric patients with haematological / immunological disorders, mainly within the last year of life, as described by another study.²⁹

As expected, elective inpatient episodes related to patients with malignancy disorders or with technology dependence or transplantation regarding planned treatment or procedures were mostly found (this is probably the reason why

shorter hospital stays have been found in these patients).

A higher percentage of inpatient episodes regarding malignancy and haematological / immunological disorders has also been found in group IV hospitals, which could be explained by the fact that the Portuguese Oncology Institutes are included in this hospital group (ensuring two of the four Portuguese paediatric oncology units in Lisbon and in Porto, in which almost all paediatric stem-cell transplants are carried out).

Most episodes regarding the remaining categories have occurred in group III hospitals, except those related to patients with neonatal diseases (in which a more balanced distribution between groups I to III hospitals has been found, probably reflecting unplanned births or unexpected childbirth problems, in line with the higher rate of urgent admissions within this category). Neonatal inpatient episodes were the longest and involving the highest costs, which is expectable due to the characteristics of these admissions, mostly within specialised intensive care units and related to patients with multiple medical or surgical problems.

A higher rate of readmission and higher mortality have been found in paediatric patients with multiple CCC.^{15,31,35} Whenever technology dependence existed, a 3.5 times higher cost has been found when compared to patients without CCC and no technology dependence.¹⁸ Inpatient episodes related to patients with more than one CCC category were 2-3 times longer in mainland Portugal, involving 2.8 times higher costs and 78 times higher mortality when compared to those without CCC. In the USA, the length of stay was three times longer in 2006, costs were 11 times higher and mortality was 15 times higher.¹⁵ The different costs in mainland Portugal and in the USA were probably related to the higher healthcare costs in the USA.

A previous Portuguese study had already showed that around 80% mortality in paediatric patients with CCC have occurred within the hospital,³ probably due to the lack of response at home or within the community. Most of the mortality of paediatric patients has occurred in intensive care units, usually involving excessive medical intervention and scarce discussion and planning regarding healthcare and end-of-life options.^{36,37} Improved communication and decision procedures are crucial within these units, in line with the patient's and family's aims.³⁸

The experience of an inpatient episode is rarely positive. The admission of a paediatric patient is in fact a disruptive event to the family³⁹ and the presence of mistakes is more likely (3 vs. 1.3/100 discharges) in patients with chronic diseases, increasing with the number and severity of CCC and the length of stay.⁴⁰

In addition, families wish to get involved in decision and in planning, as well as to be involved in their children's healthcare, within a resilient perspective of normalisation of daily life.⁴¹ Quality improvement programs involving medically complex patients, focused on family empowerment and healthcare coordination, lead to the reduction of inpatient episodes, the length of stay and costs as well as to an improvement of the clinical outcomes and family

satisfaction.^{42,43}

The education of professionals is also crucial, particularly regarding paediatric registrars, aimed at the healthcare of these patients,¹⁷ while also in adult patient departments, as the increasing survival of patients will raise the need for a transition in healthcare within these departments which in most cases are currently not adequately prepared.⁴⁴

Finally, the increasing health expenditure is a global concern in search for solutions and is also worth mentioning. One of these could be the integration of paediatric palliative care as health expenditure is not increased with the application of the principles of promotion of the quality of life and could even be reduced, mainly in the end of life stages^{45,46} or when provided within the community, including at home.^{47,48}

For all these reasons, the development of paediatric palliative care programmes in hospitals taking care of paediatric patients with CCC should be considered,^{17,49–51} involving multidisciplinary teams and providing guidelines and/or healthcare both to inpatients and outpatients (or even within home care), as recommended in 2014 to the Ministry of Health by a group of experts.²³ Even though families could at first 'worry' about these teams, not understanding their contribution to their children's healthcare, their involvement will end up to be valued. The attitude of these professionals and their practical support, case management, planning and healthcare continuity are particularly appreciated by families.⁵² The increasing number of paediatric palliative care departments in different countries reflects the evidence of their efficacy and positive outcomes (there were already 112 in 2013 in the USA, described by 69% of the respondents to a survey).⁵³

Strengths

Needs estimation is easily available by the use of a national hospital database supplied with routine data (with a residual number of absent information within the relevant variables of this study) and involving a large number of episodes. In addition, it will allow for a comparison in a few years, following the expected implementation of paediatric palliative care services. Our option by the application of a robust classification of the target population is also worth mentioning, by using its first version¹ in similar studies from other countries.^{15,17,18,29} However, the authors of the classification warned that an increasing sensitivity of version 2 in the identification of paediatric patients with CCC might lead to a reduction in specificity.¹⁶

Limitations

This study is limited in several regards. At first, a correct codification of all the episodes could not be ensured and an underestimation of the number of episodes related to patients with CCC is more likely. Secondly, when inter-hospital transfers of patients have occurred, inpatient episodes were recorded in both hospitals and we have decided not to exclude these due to the fact that each episode represents an activity within each hospital (even though regarding the

same patient and condition). In addition, data on inpatient location (in a ward or intensive care unit) or the patient's condition severity or stage were not available. The study of these two aspects would deepen the knowledge on the national patterns of paediatric inpatient use by patients with CCC. For instance, English children with life-limiting conditions are involved in 57.6% of admissions and 72.9% of mortality in paediatric intensive care units.⁵⁴ In fifth place, due to anonymised data, this database could not be linked to others, which would enrich the analysis regarding socio-demographic aspects. Finally, indirect costs associated with inpatient episodes were not taken into consideration (including extra-costs to the family, loss of income, work and school absenteeism).

CONCLUSION

This study allowed for the conclusion that medically complex paediatric patients living in mainland Portugal, with palliative needs, represent a very relevant part of the activity and costs of paediatric inpatient episodes. This conclusion is crucial for an efficient, coordinated and sustainable healthcare planning,^{4,16} giving a contribution to political decision-makers in taking informed resolutions and in meeting current and future needs of patients and professionals of the Portuguese SNS (*Sistema Nacional de Saúde*). The increasing prevalence of CCC is worth mentioning and represents a pressure on resources and financial support of the healthcare system.⁶

Welfare of patients with CCC and their families should be a concern of the whole society,⁵ considering that a healthcare model adapted to their needs is required, instead of the traditional disease-centred model.⁴

As intensive utilisers of the resources of the SNS, these patients should represent a major target for the development of reforms aimed at the coordination and timely planning of care (in health, education and social security),³⁵ as recommended by the basic principles of paediatric palliative care.¹⁹ Future research should be focused on the psycho-social aspects, namely the attitudes, values and preferences of Portuguese paediatric patients with CCC and their families.

Lower healthcare service consumption is found in families feeling well in their daily living, feeling involved, supported and guided within complex healthcare. The development of patient-oriented healthcare models and oriented to the family well-being is a current obligation of paediatrics⁵ and a reflection on the user's needs is mandatory.

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HUMAN AND ANIMAL PROTECTION

The authors declare that the followed procedures were according to regulations established by the Ethics and Clinical Research Committee and according to the Helsinki

Declaration of the World Medical Association.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data. Informed consents were obtained.

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