

## Analysis of the cost of care for children and adolescents with medical complex chronic conditions

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**Abstract** *This paper aimed to identify the use of technology and to analyze the cost of hospital care for children and adolescents with medical complex chronic conditions at a public federal hospital specialized in high-complexity pediatric care, and was performed concomitantly with a prospective cohort study conducted over a one-year period. It included 146 patients with complex medical chronic conditions and 37 non-chronic patients. The analysis showed that most patients had, on average, two hospitalizations a year and were diagnosed with diseases related to at least two organic systems. Catheters, drains and gastrostomy were the most common technologies used. Median direct costs of patients with medically complex chronic conditions were higher than those of non-chronic patients when comparing the use of technology. The study shows high hospitalization cost to these patients. Technology use and hospitalization care costs documentation yields more data to support decision-makers in the planning, managing, and financing of pediatric health policies.*

**Key words** *Child, Youth, Chronic disease, Cost and cost analysis.*

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## Introduction

In 2003, the World Health Organization addressed the need for reorganizing health systems care to people with chronic health conditions, considering the transformations in the epidemiological scenario<sup>1</sup>. Within this group, it is urgent to recognize the complex health care needs of children and adolescents with limited physical or mental functions, which require multi-professional care coordination among various health sectors, with particular emphasis on rehabilitation, dependence on multiple medications and feeding, breathing and excreting technology<sup>2-4</sup>. These groups are recognized in the literature as Children with Special Health Care Needs, Technology-Dependent Children, Children with Complex Medical Conditions<sup>2,4,6</sup>. In this paper, we use the term Chronic Complex Health Condition (CCC) to categorize children and adolescents, which allow the synthesis of situations triggered by life with chronicity: symptoms duration greater than twelve months, compromising one or more organic systems simultaneously and requiring specialized pediatric care in tertiary care centers.

CCCs are life-long and produce costly situations to patients and their families. They demand family and community adaptations, and an efficient health system<sup>3,4,7-10</sup>. The “chronic conditions” category includes a group of CCC children and adolescents whose prevalence is increasing due to reduced child mortality, access to new technologies, and improved social and health markers<sup>7,11</sup>. In developed countries, it is estimated at approximately 16% in the population up to 18 years of age<sup>4</sup>. Thirty years ago, children with these conditions would not survive<sup>12</sup>. However, we can observe that they may be treated and indeed survive with medically fragile profiles and special health care needs<sup>3</sup>.

CCC children and adolescents are high users of technology and human resources through prolonged hospitalizations. The discharge processes involve many negotiations with stakeholders in other sectors of society – family, the Judiciary, primary health care, and social assistance services<sup>13</sup>. These patients are technology-dependent and with a fragile clinical situation during hospitalization, and subject to instability and deteriorated condition. Moreover, although they are a smaller portion of the population, this CCC group accounts for a significant proportion of hospital expenditure<sup>4</sup>. Thus, estimating the cost of health care has been an object of analysis in developed countries<sup>14,15</sup>.

The health emergency of the Zika virus epidemic in Brazil in 2015 highlights this discussion, considering that babies born with microcephaly or the various diseases caused by Congenital Zika Syndrome will be part of the group of children growing up with CCC<sup>16</sup>. The Ministry of Health estimates that 29% of Brazilian municipalities have reported cases of microcephaly and nervous system changes<sup>17</sup>.

This paper contributes to the systematization and analysis of data on the cost of healthcare for hospitalized CCC children and adolescents and the use of health technologies. These conditions demand a wide range of health services that are challenging to the Brazilian Unified Health System (SUS). These new and emerging health problems, which encompass multiple complexities, call for a definition of adequate resources for professional training, programming on life-support technology demands, networking, and adequate funding<sup>12</sup>.

The Brazilian literature systematizing patterns of technology use and medical costs is still scarce. Discussing these patterns in the group of CCC children and adolescents becomes an important issue given the relevance of their participation in the health sector budget in both national and international settings<sup>14,18</sup>. This study is part of broader research that systematized the hospital morbidity profile of admitted children and adolescents, and aimed to calculate the direct cost of medical care of a cohort of hospitalized CCC patients.

## Methods

This is a retrospective analysis of a cohort of CCC patients conducted between May 2014 and April 2015. All patients aged 0 to 18 years hospitalized for 12 months at the Fernandes Figueira National Institute for Women, Child and Adolescent Health (IFF), a federal public hospital specialized in pediatric care, located in and covering the city of Rio de Janeiro, were included. The hospital is a reference center for children and adolescents with rare diseases in Brazil. These diseases can be clinically identified as CCC, which means that research conducted in this setting may reflect its national demands. The institution's Research Ethics Committee approved the study.

The chronic or non-chronic condition of the child was defined on admission. Any non-chronic patient undergoing technology-assistance procedures, such as tracheostomy and gastrostomy,

would be included in the CCC group. Patients were identified from the classification proposed by Feudtner et al.<sup>19</sup> and updated by the International Classification of Diseases – 10<sup>th</sup> Revision (ICD-10). A new version of that classification was published in 2014, adapting CCC diagnosis to ICD-10. Three new categories were added, namely, diagnoses of origin in the neonatal period, transplants, and technology dependence<sup>20</sup>. This update was confirmed in this study by consulting pediatric experts with experience in medical care for children and adolescents diagnosed with CCC.

Patients readmitted and transferred from other sectors of the hospital – general pediatrics outpatient clinic, specialized outpatient clinics, pediatric neonatal and intensive care units, pediatric surgery and infectious diseases wards, and semi-intensive and inpatient units – were included in the period of cohort follow-up. Thus, CCC patients were divided into the following groups, as per the ICD-10: respiratory, metabolic, neuromuscular, cardiovascular, renal, gastrointestinal, hematological diseases, immunodeficiencies, psychiatric disorders, congenital or genetic disabilities, and cancer.

Then, from the clinical profile, the study population was subdivided into: i. Patients using technologies indicative of complexity: tracheostomy, gastrostomy, use of drains (chest, peritoneal or subgaleal) and catheters (peritoneal ventricle shunt, deep venous or peripheral insertion), use of oxygen therapy, invasive mechanical ventilation, special infant formulas, and antibiotic therapy; ii. Number of diagnoses as per the ICD-10 groups associated with CCC; iii. Origin of patients readmitted or transferred from other sectors of the hospital; and iv. Clinical outcomes: discharge with and without technology, hospital stay until the end of the study, and hospital death.

We estimated the direct medical cost from the SUS perspective. We applied the cost per patient method, which considers each patient path through different services. The absorption costing per hospital cost center system allowed the valuation of health resources. The total direct cost per patient was calculated, considering the daily hospital cost of each service used by the patient. The cost items included tests (laboratory and imaging), materials, medicines, special milk formulas, human resources, use of oxygen therapy and overhead costs (electricity, telephone, water, cleaning, safety, collection of chemical and environmental waste and laundry). The time horizon was one year and did not consider the

period before and after the beginning and end of the cohort. No discounts or inflationary adjustments were applied due to the short time span. The cost refers to 2016 Brazilian Reais (R\$).

CCC patients and non-chronic patients' costs were compared and included, based on the use of the following medical technologies prescribed for both groups: special dairy formulas, antibiotic therapy, oxygen therapy, noninvasive ventilation, and imaging tests (x-ray, tomography, ultrasound, and echocardiography). We hypothesized that CCC patients would have higher health resource consumption than non-chronic patients and, therefore, higher costs.

The total direct cost per patient was aggregated and shown, in absolute values, as the total direct median cost of care of CCC patients and non-chronic patients. Costs were displayed as median, minimum and maximum values, whereas categorical variables were expressed as absolute frequencies and percentages. We carried out regression analyses using the Generalized Estimating Equations (GEE) model to verify the impact of comorbidities, patient origin, length of stay, and procedures on the total hospitalization cost. We apply the logarithmic transformation to fit the above model as the response variable, in this case, the total direct cost of the CCC patients did not have a Normal distribution. The Kolmogorov-Smirnov test was used to assess the normality assumption. The SPSS 18 (SPSS Inc. Release VCSI. SPSS Statistics for Windows, version 18, IL, USA) and R 3.2.2. (R Core Team. Foundation for Statistical Computing V, Austria, version 3.2.2) software were used for data analyses with a significance level of 5%.

## Results

A total of 183 patients were included during the study period, of which 146 (79.8%) had CCC. Non-chronic patients totaled 37 individuals (20.2%), with 241 hospitalizations. The CCC group had a median age of one year and a median hospital stay of 11 days (mean: 35 days; standard deviation: 72 days). Table 1 shows that of the total CCC patients, 35.7% had diseases involving at least two organic systems, 62.4% three systems, and approximately 92% had two yearly hospitalizations. The most frequent hospitalizations were recorded among patients diagnosed with genetic or congenital defects (78.1%), respiratory (64.4%), and neuromuscular (50%) diseases. The use of drain or catheter (39.7%) and

gastrostomy (15.8%) were the most commonly employed technologies during hospitalization.

Table 2 shows the comparison between CCC patients and non-chronic patients, and the total median cost of the first group was higher, ranging from 60% for hospitalization for the diagnosis of respiratory diseases, to 657% for tomography. The cost of procedures performed during treatment ranged from 133% to 339% between the two groups.

Regarding CCC patients, the regression model results showed that the length of stay (LOS), the number of systems affected, the patient's origin service, the outcomes and the need for technologies at hospital discharge significantly increased the cost. The total median cost was directly proportional to the length of hospital stay (Figure 1a) and highly sensitive to the number of diseases/organic systems affected (Figure 1b), and the highest cost was for CCC patients diagnosed with respiratory and metabolic diseases (Figures 1c and 1d). The other categories of diseases classified by ICD-10 (neuromuscular, cardiovascular, renal, gastrointestinal, hematological or immune deficiency, psychiatric disorders, and genetic or congenital disabilities and cancer) were not statistically significant for the total median cost.

The cost of CCC patients from two pediatric inpatient units – semi-intensive and inpatient – was higher than estimated for the other hospital sectors. The lower cost was associated with patients from specialized outpatient clinics when compared to those from inpatient units (Figure 2a). Patients who remained hospitalized at the end of the study period recorded the highest total median cost among the outcomes studied, followed by those who died and those who were discharged (Figure 2c). This is probably due to the median LOS of 77.5 days, 21.5 days, and 10 days for hospitalization, death, and discharge, respectively. The total median cost of patients requiring technologies at hospital discharge was also high (Figure 2c).

## Discussion

The median age of one year in the sample reflected the predominance of congenital conditions and pointed to the complexity of the cases, as there was a significant burden associated with CCC, evidenced by the presence of three or more diagnoses, a scenario also observed in the American program *Medicaid*<sup>14</sup>. It is noteworthy that almost all patients (97%) recorded up to three

**Table 1.** Clinical characteristics and technology use of patients in a federal public hospital, 2016.

Clinical characteristics	n	%
Complex chronic condition	146	79.8
Non-chronic	37	20.2
Use of technologies during hospitalization		
Tracheostomy	7	4.8
Gastrostomy	23	15.8
Drain/catheter	58	39.7
Ventricular cerebrospinal fluid shunt	8	5.5
Hospitalizations		
One	106	72.6
Two	28	19.2
Three	8	5.5
Four	3	2.1
Five	1	0.7
Diseases		
Genetic or congenital defects	114	78.1
Breathing	94	64.4
Neuromuscular	73	50.0
Gastrointestinal	62	42.5
Cardiovascular	43	29.5
Metabolic	27	18.5
Kidney	20	13.7
Hematologic and immunodeficiencies	10	6.8
Psychiatric disorders	1	0.7
Cancer	1	0.7
Diagnostics Associated with CCC (ICD-10)		
One	16	11.0
Two	36	24.7
Three	39	26.7
Four	38	26.0
Five	15	10.3
Six	2	1.4

ICD-10: International Classification of Diseases - 10th Revision.

hospitalizations during the study period, and the literature shows that one of the leading predictive variables for pediatric hospitalizations, readmissions, and hospital expenses are admissions with two or more CCCs<sup>7,15</sup>.

The cost of medical care for CCC patients was higher than non-chronic patients cost, and proportionally increased concerning the LOS, as expected. Respiratory and metabolic diseases were the CCC groups responsible for the highest cost. In our study, cystic fibrosis, a progressive

**Table 2.** Median total cost of patients with complex chronic health condition and non-chronic patients hospitalized in a federal public hospital, 2016.

Variable	Non-chronic patients (R\$) <sup>a</sup>	Patients with complex chronic health condition (R\$) <sup>a</sup>	p-value*
	(n=37)	(n = 146)	
<b>Technology use</b>			
Special Milk Formulas	18.507,64 (2.022,45 – 40.449,00)	40.449,00 (2.022,45 – 792.562,68)	<0,01
Antibiotic Therapy	12,134.70 (2,022.45 – 169,834.86)	28,314.30 (2,022.45 – 792,562.68)	<0.01
Oxygen therapy	12,134.70 (2,022.45 – 169,834.86)	31,421.19 (2,022.45 – 762,079.50)	<0.01
Noninvasive mechanical ventilation	9,798.16 (8,709.48 – 10,886.85)	43,009.43 (4,354.74 – 762,079.50)	<0.01
Imaging tests	11.510,78 (2.022,45 – 169.834,86)	26.291,85 (2.022,45 – 792.562,68)	<0,01
X-ray	12.134,70 (2.022,45 – 169.834,86)	26.291,85 (2.022,45 – 792.562,68)	<0,01
Computed tomography	8.709,48 (2.022,45 – 169.834,86)	65.953,52 (2.022,45 – 792.562,68)	<0,01
Ultrasound	16.179,60 (6.067,35 – 169.834,86)	56.628,60 (4.044,90 – 792.562,68)	<0,01
Echocardiography	16.799,28 (6.067,35 – 169.834,86)	55.617,38 (2.022,45 – 792.562,68)	<0,01
<b>Associated comorbidities</b>			
Respiratory diseases	10.499,55 (2022,45 – 169.834,86)	26.291,85 (2.022,45 – 73.6171,80)	<0,01
Gastrointestinal diseases	15.241,59 (14.157,15 – 20.224,50)	28.314,30 (2.022,45 – 79.2562,68)	<0,01
<b>Diagnosis of hospitalization</b>			
Respiratory diseases	10,112.25 (2,022.45 – 40,449.00)	16,179.60 (2,022.45 – 729,418.95)	<0.01

R\$ = Brazilian Reais.

a Cost shown as median value (minimum – maximum).

\* p-value: concerning the adjustment of the generalized estimating equation model, considering the total cost logarithm as an outcome and the presence or absence of a complex chronic health condition as the predictive variable.

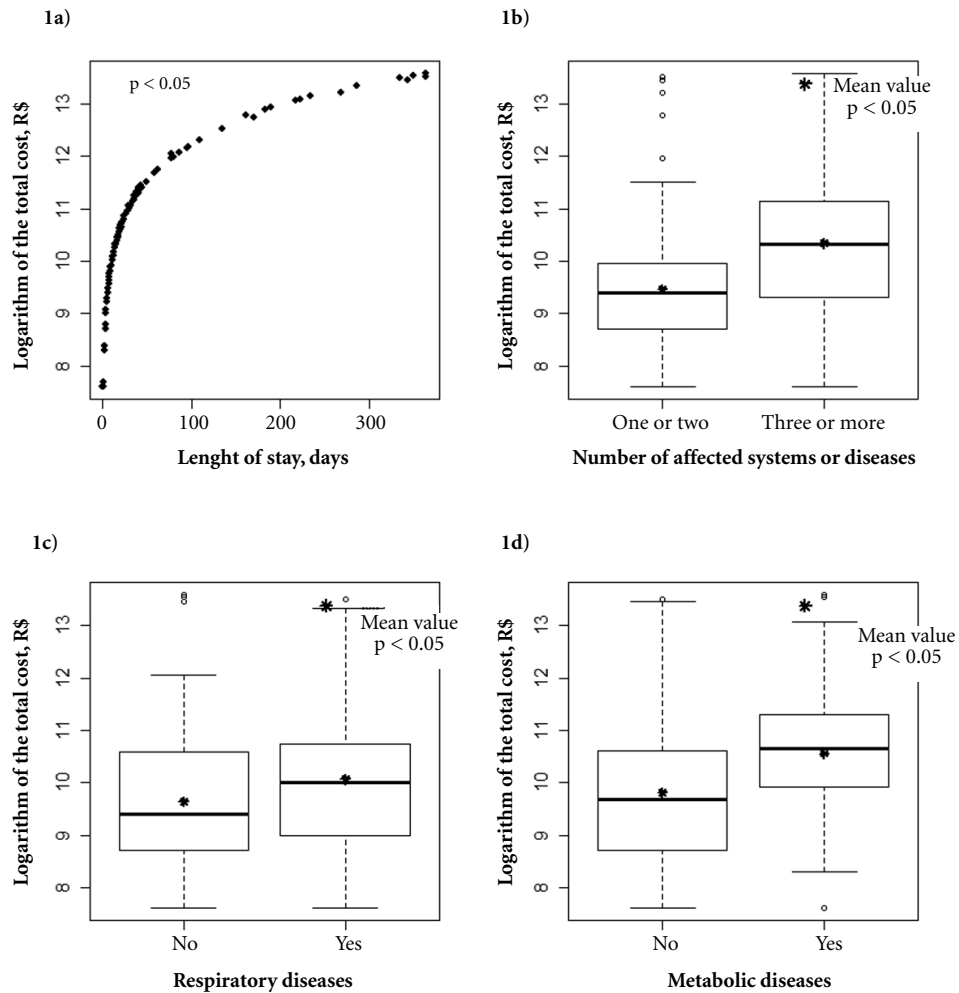
multisystemic disease, accounted for the largest group of metabolic diseases, which could explain the higher proportion of costs as observed in other countries<sup>21</sup>. Cystic fibrosis patients and other complex conditions, including those with technology dependence, survive longer than in the past and have special health care needs requiring significant financial, hospital and community resources<sup>12,21</sup>.

In this study, the total median cost of patients who died was higher than the discharged, suggesting different patterns of chronicity and complexity and more intensive use of health resources. The study by Miller et al.<sup>22</sup> corroborates this result by showing that patients' LOS was inversely proportional to clinical severity when compared to extremely severe and moderately severe patients, resulting in a higher total cost for the former. While we did not aim to estimate the "cost of death", it is worth reflecting on the challenges and constraints imposed by clinical complexity and the resources required to address them in the daily scenario. The sentence "death has a cost" points to two issues: the costs to families concerning the demands of comprehensive and

permanent care, and the therapeutic obstinacy of health professionals supported by technological and therapeutic advances. The prolonged lifetime may require measures that are sometimes necessary to meet the needs of some patients, but they could be extraordinary for others<sup>23</sup>.

Regarding the result of the higher total median cost among patients with CCC from semi-intensive care units and inpatients, future studies would benefit from discussing the path that includes birth in adverse situations leading to technological dependence and the realization of surgical procedures, extending hospital stays over the years. This is reflected in this study when we compare the patients' origin, understood as their entry point in the research, with the result of the total cost of medical care.

The hospital under study is equipped with a semi-intensive unit working as a prolonged mechanical ventilation weaning unit, which prevents pediatric intensive care beds from being blocked by mechanical ventilation-dependent CCC patients. Consequently, we believed that the cost could be even higher had they remained in intensive care, potentially avoiding access to acute and



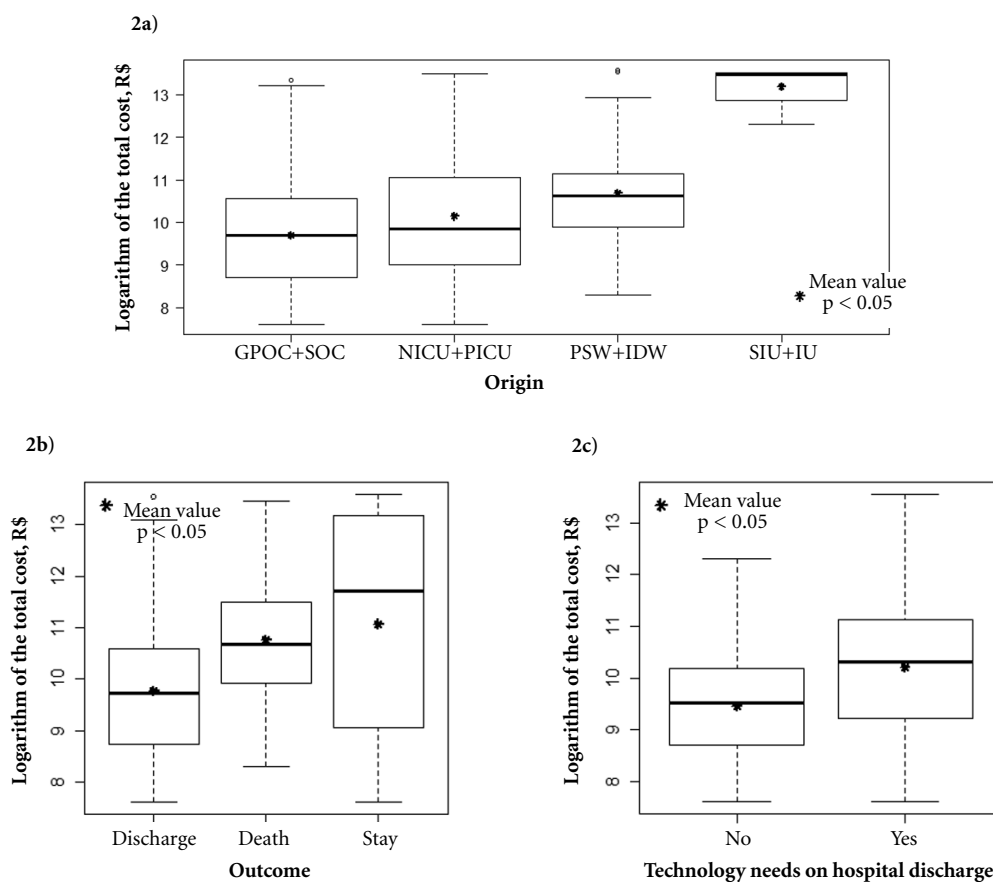
**Figure 1.** Logarithm of the total cost of hospital care of patients with complex chronic health conditions concerning length of stay, number of systems affected or diseases and presence of respiratory and metabolic diseases in a public hospital, 2016.

R\$ = Brazilian Reais

unstable patients<sup>24</sup> who would benefit most from this specialized care. This issue highlights the need for the organization of services to care for this group of mechanical ventilation-dependent CCC patients. It also demands the articulation and organization of the in-hospital, outpatient and emergency health services network, which is confronted with the health needs of the pediatric population in the state of Rio de Janeiro<sup>25</sup>.

This study has some limitations. It was performed in a single tertiary hospital, which hinders generalization of the results and restricts their comparison with other lower complexity

hospitals. However, it has been argued<sup>7</sup> that the hospital is the best locus to observe and analyze the increasing number of CCC children and adolescents since this group has frequent hospital readmissions, and CCCs can be developed during their illness. A second limitation refers to the time horizon since the total median cost was calculated for one year. Some cohort patients were already hospitalized before the start of the study, and prior use of resources was not considered. Patients also demand lifelong resources and outpatient visits, and the cost to families was not included. This component should be incorporat-



**Figure 2.** Logarithm of the total cost of hospital care of patients with complex chronic conditions concerning origin, outcome and need for technology at hospital discharge.

R\$ = Brazilian Reais; APG: general pediatric outpatient clinic; AE: specialized outpatient clinics; Neo: neonatal intensive care unit; ICNP: pediatric surgery ward; DIPE: infectious disease ward; IU: semi-intensive unit; UPI: impatient unit.

ed into future research as it is higher for technology-dependent children<sup>15,26-28</sup>. It is also noteworthy that the total median cost increased with the number of diseases and systems affected. We did not aim to compare this cost by discriminating which systems were affected, but instead to understand how complexity could affect technology use, LOS, and cost. As a result, the outcomes may be underestimated, and we suggest that future research in this field be expanded in Brazil in order to identify the cost from the perspective of society.

It is worth pointing out the relevance of planning dehospitalization actions in the care line for these patients, considering the cost generated by technological dependence and repercussions on

the health system and families. Other demands are also added, such as access to social security benefits, transportation services for continuous, out-of-home treatment, and home adaptations<sup>13</sup>. Dehospitalization programming can be a complex process including multidisciplinary approaches, involving different health care levels to ensure that each patient remains healthy, develops, and receives support for ongoing care at home<sup>29</sup>. In the discharge planning, the emotional burden imposed on families when taking on the daily home care of CCC patients should also be considered.

In Brazil, a change in the pediatric hospital profile has been observed over the last decades<sup>25,27</sup>. A transition to “new pediatrics”<sup>30</sup> faces

health professionals to new challenges. As the prevalence of CCC increases globally, it is important to document health resource utilization and cost, even at the local level, and to understand the obstacles to plan the health system for CCC children and adolescents effectively.

### **Collaborations**

M Pinto: study design and planning, data collection, statistical analysis and interpretation, manuscript drafting and review. MCN Moreira: study design and planning, data collection, statistical analysis and interpretation, manuscript drafting and review. RF Tanabe: study design and planning, data collection, statistical analysis and interpretation, manuscript drafting and review. ACC Costa: data collection, statistical analysis and interpretation, manuscript drafting and review. R Gomes: manuscript drafting and review.



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