

## Complex chronic conditions in children and adolescents: hospitalizations in Brazil, 2013

Condições crônicas complexas em crianças e adolescentes: internações no Brasil, 2013

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**Abstract** *This article aims to estimate the extent of hospitalizations for complex chronic conditions in Brazil. Data from the Hospital Information System for 2013 were compiled according to the International Classification of Diseases 10<sup>th</sup> Revision. Hospitalization rates were estimated according to region, sex, age and disease chapter, taking into account the 2012 population as a reference, as well the percentage of highly complex procedures and mortality rates. Public hospitals treated 190,000 inpatients in 2013. The rate was highest among the population in the South of Brazil, those who were male and children under the age of one. The rate was lowest among the population in the North, females and children aged between 10 and 14 years. The mean duration of hospitalization was six days, the percentage of highly complex procedures was 13.5% and the mortality rate was 1.3%. The three most common causes for hospitalizations were diseases of the respiratory system, neoplasms and diseases of the nervous system. The incidence of complex chronic conditions is 331 inwards per 100,000 children and adolescents in Brazil, with an estimate of 240,000 children and adolescents hospitalized. This panorama points to the problem as an emergent public health issue in Brazil.*

**Key words** *Chronic disease, Children, Adolescents, Hospitalization, Brazil*

**Resumo** *O objetivo deste artigo é estimar a magnitude das internações por doenças crônicas complexas no Brasil. Dados do Sistema de Informações Hospitalares referentes a 2013 foram compilados de acordo com a Classificação Internacional de Doenças 10<sup>a</sup> revisão. Taxas de internação foram estimadas de acordo com a região, sexo, idade e doença, tendo como referência a população de 2012, bem como o percentual de procedimentos de alta complexidade e as taxas de mortalidade. Hospitais públicos tiveram 190.000 pacientes internados em 2013. A taxa foi maior entre a população do Sul do Brasil, entre homens e crianças menores de um ano de idade. A taxa foi menor entre a população do Norte, entre mulheres e crianças de 10 a 14 anos de idade. A duração média de internação foi de seis dias, a porcentagem de procedimentos de alta complexidade foi de 13,5% e a taxa de mortalidade foi de 1,3%. As três causas mais comuns para internações foram as doenças do sistema respiratório, neoplasias e doenças do sistema nervoso. A incidência de hospitalização por doenças crônicas complexas foi 331 para 100.000 crianças e adolescentes no Brasil, com uma estimativa de 240.000 crianças e adolescentes hospitalizados. Esse panorama aponta para as doenças crônicas complexas como problema emergente em saúde pública no Brasil.*

**Palavras-chave** *Doença crônica, Crianças, Adolescentes, Hospitalização, Brasil*

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## Introduction

Chronic conditions include a wide range of health problems: non-transmissible conditions, persistent transmissible conditions, irreversible mental disorders and physical/structural deficiencies, all of which limit functionality, as well as infectious diseases including the human immunodeficiency virus (HIV) and tuberculosis that demand continuous and long-term treatment<sup>1</sup>.

This generic definition does not make it any less important to better understand cases of complex chronic conditions (CCC) according to the life cycle. CCC in childhood and adolescence includes multi systemic, congenital and acquired diseases. The main characteristics of CCC are functional limitations, specialized care needs and technological dependence<sup>2</sup>. CCC is irreversible and represents a high social cost for patients and their families, demanding household and community adaptations, as well as an agile health system with high complexity and multiple professional assistance<sup>3-7</sup>.

The prevalence of CCC among children and teenagers is growing around the world because of the reduction in infant mortality, improvements in surgical techniques and biomedical engineering, increased immunization cover and healthcare and improvements in social indicators. In the United States of America, CCC accounted for almost 16% of the hospitalized population under the age of 18 years in the year 2000<sup>8</sup>, and saw the hospitalization rate of children under four double from 1991/93 to 2003/05<sup>9</sup>. The number of children aged less than 18 years hospitalized for CCC in the USA also increased between 1997 and 2006<sup>10</sup>. In 2009 in Santiago, Chile, CCC accounted for approximately 60% of hospitalizations for children under the age of 15 years<sup>11</sup>. In Canada<sup>12</sup>, data from three national studies between 2001 and 2004 showed CCC prevalence to be between 13% and 18% among children and adolescents (under 18years).

In Brazil, prevalence data about CCC are not yet available, but an increase of cases is also expected, resulting in an increased demand for care and hospitalization. Then, it is not possible to retract any epidemiological status. This article is the first in this subject and aims to estimate the magnitude of CCC hospitalizations in Brazil, thereby seeking to support health planning in this subject and providing epidemiological data.

## Methods

In Brazil, all public and some private hospitals contracted by the Brazilian Health System provide electronic data on patients immediately after being discharged through the Ministry of Health's National Hospital Information System. In this way, health institutions are reimbursed for part of the costs of hospitalizations. For this analyses, data about CCC hospitalizations for all children and adolescents aged less than 18 years old, in those hospitals, were compiled from data composed by the Minister of Health collected directly from the primary source – the admission guide, which is provided by each hospitalization. All the hospitalizations from 2013 were retrospectively analyzed, characterizing it as a survey study.

For this study, a disease list of CCC was compiled, based on the International Classification of Diseases (10<sup>th</sup> Revision; ICD-10)<sup>13</sup>, Feudtner et al.<sup>14</sup> and clinical opinion (Chart 1).

Data from 2013 relating to the list were drawn from the Information System and the number of inpatients was disaggregated by region, sex, age and ICD-10 chapter<sup>13</sup>. The year 2013 was chosen because this was the most recent year for which all national data had been consolidated.

Data were tabulated and analyzed with the assistance of the Statistical Package for the Social Sciences. Proportions of hospitalizations were calculated for each category, considering a confidence interval of 95%. Hospitalization rates were also estimated taking into account the 2012 population as a reference.

Additionally, besides to estimate the magnitude of CCC hospitalizations, the duration of the hospitalization, the percentage of highly complex assistance and mortality rates were calculated enabling the three most common groups to be identified and analyzed according to ICD identification.

## Results

In 2013, public hospitals received 190,000 inpatients (Table 1), meaning a rate of 331 hospitalizations per 100,000 inhabitants aged less than 18 years old. The South Region had the highest rate and the North the lowest. The rate is higher among male inpatients, and the rate for children under the age of one year was above 1,000 per 100.000 inhabitants.

**Chart 1.** Diagnoses of chronic clinical conditions, according to International Classification of Diseases (10<sup>th</sup> Revision; ICD-10) chapter, subcategory and code.

Chapter	Subcategory	Code
Certain infectious and parasitic diseases	Human immunodeficiency virus (HIV) disease	B20-B24
Neoplasms	Neoplasms	C00-D48
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	Anaemia due to enzyme disorders	D55
	Thalassaemia	D56
	Sickle-cell disorders	D57
	Other hereditary haemolytic anaemias	D58
	Acquired haemolytic anaemia	D59
	Combined immunodeficiencies	D81
	Immunodeficiency associated with other major defects	D82
Endocrine, nutritional and metabolic diseases	Common variable immunodeficiency	D83
	Metabolic disorders of amino-acids	E70-E72
	Metabolic disorders of carbohydrates	E73-E74
	Metabolic disorders of lipids	E75
	Combinations of metabolic disorders	E76-E78
Mental and behavioral disorders	Cystic fibrosis	E84
	Mental retardation	F70-F79
	Disorders of psychological development	F80-F89
Diseases of the nervous system	Hyperkinetic disorders	F90
	Multiple sclerosis	G35
	Other acute disseminated demyelination	G36
	Other demyelinating diseases of central nervous system	G37
	Epilepsy	G40
Diseases of the circulatory system	Cerebral palsy and other paralytic syndromes	G80-G83
	Cardiomyopathy	I42-I43
Diseases of the respiratory system	Other conduction disorders.	I45-I49
	Bronchitis; Emphysema; Other chronic obstructive pulmonary disease	J40- J44
	Asthma; Status asthmaticus	J45-J46
Diseases of the digestive system	Bronchiectasis	J47
	Crohn's disease ,	K50
	Ulcerative colitis	K51
	Other noninfective gastroenteritis and colitis	K52
Diseases of the genitourinary system	Diseases of liver (except alcoholic)	K71-K77
	Renal failure	N17-N19
Congenital malformations, deformations and chromosomal abnormalities	Nervous system	Q00-Q07
	Circulatory system	Q20-Q28
	Respiratory system	Q30-Q34
	Congenital malformations of digestive system	Q39- Q40; Q42-Q43
	Congenital absence, atresia and stenosis of small intestine	Q41
	Urinary system	Q60-Q64
	Congenital malformations of the musculoskeletal system, not elsewhere classified	Q79.0-Q79.4
	Chromosomal abnormalities, not elsewhere classified	Q90-Q99

**Table 1.** Distribution of hospitalizations by chronic clinical conditions (number, percentage with respective confidence interval of 95% and rate per 100,000 inhabitants) by region, age and chapter of the International Classification of Diseases (10<sup>th</sup> Revision; ICD-10), Brazil, 2013.

		n	%	CI <sub>95%</sub>	Rate*
Region	North	15,433	8,6	8,5-8,7	252
	Northeast	61,909	33,0	32,8-33,2	354
	Southeast	66,467	34,6	34,4-34,8	306
	South	29,464	15,6	15,4-15,7	394
	Middle-West	15,773	8,3	8,1-8,4	366
Sex	Male	103,319	54,7	54,4-54,9	356
	Female	85,727	45,3	45,1-45,6	305
Age (year)	< 1	28,902	15,3	15,1-15,5	1004
	01 a 04	63,973	33,8	33,6-34,1	573
	05 a 09	43,761	23,1	23,0-23,3	287
	10 a 14	32,215	17,0	16,9-17,2	184
	15 a 17	20,195	10,7	10,5-10,8	195
ICD-10	Certain infectious and parasitic diseases	1,082	0,6	0,5-0,6	2
	Neoplasms	45,657	24,2	24,0-24,3	80
	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	7,194	3,8	3,7-3,9	12
	Endocrine, nutritional and metabolic diseases	3,495	1,8	1,8-1,9	6
	Mental and behavioral disorders	1,372	0,7	0,7-0,8	2
	Diseases of the nervous system	23,724	12,5	12,4-12,7	42
	Diseases of the circulatory system	2,624	1,4	1,3-1,4	5
	Diseases of the respiratory system	79,829	38,3	37,4-39,1	140
	Diseases of the digestive system	7,237	3,8	3,7-1,8	13
	Diseases of the genitourinary system	3,355	1,8	1,7-1,8	6
	Congenital malformations, deformations and chromosomal abnormalities	13,477	7,1	7,0-7,2	24
	Total		189,046	100,0	-

The mean duration of hospitalization was six days, ranging from zero to 353. Only 13.5% of hospitalizations required highly complex care and the mortality rate was 1.3%. The three most frequent causes of hospitalization were diseases of the respiratory system, neoplasms and diseases of the nervous system.

For all patients aged less than 18 years old, among diseases of the respiratory system, the three most common were asthma (83.0%), bronchitis, emphysema and other chronic obstructive pulmonary disease (16.5%) and bronchiectasis (0.5%), according to ICD identification. Children under the age of one year had the highest rates. The Northeast Region had the highest rates and the Southeast the lowest. The mean duration of hospitalization for diseases of the respiratory system was 3.8 days, ranging from zero to 353.

In respect to neoplasms, in all age groups the highest rates were found in the South region

and among children aged between one and four years. The mean duration of hospitalization was 6.6 days, ranging from 5.5 days in the Mid-West Region to 9.9 days in the North.

Concerning diseases of the nervous system, the three most common diseases were epilepsy (79.3%), cerebral palsy and other paralytic syndromes (20.4%) and multiple sclerosis (0.3). The highest rate occurs in the first year of life, being higher in the South and less in the North. The duration of hospitalization for diseases of the nervous system ranged from one to 263 days, and the mean duration was 7.3.

Table 2 shows the higher percentage of male than female in all regions, as well in the group age from one to four years old. The three most common causes of hospitalization were diseases of the respiratory system, neoplasms and diseases of the nervous system. However, the percentage of hospitalization by neoplasms and diseases of

**Table 2.** Distribution (percentage with respective confidence interval of 95%) of hospitalizations by chronic clinical conditions by sex, age and chapter of the International Classification of Diseases (10<sup>th</sup> Revision; ICD-10) according to region Brazil, 2013.

		Region				
		North	Northeast	Southeast	South	Middle-West
Sex	Male	53.7 (52.9-54.4)	54.6 (54.2-55.0)	54.9 (54.5-55.3)	55.1 (54.6-55.7)	53.8 (53.1-54.6)
	Female	46.3 (45.6-47.1)	45.4 (45.0-45.8)	45.1 (44.7-45.5)	44.9 (44.3-45.4)	46.2 (45.4-46.9)
Age (year)	< 1	14.6 (14.0-15.1)	14.0 (13.7-14.2)	15.9 (15.6-16.2)	16.6 (16.2-17.1)	16.2 (15.6-16.8)
	01 a 04	35.4 (34.7-36.2)	35.1 (34.7-35.5)	32.2 (31.8-32.6)	33.7 (33.2-34.3)	34.3 (33.5-35.0)
	05 a 09	23.7 (23.1-24.4)	23.7 (23.4-24.1)	23.0 (22.7-23.3)	21.6 (21.2-22.1)	23.7 (23.1-24.4)
	10 a 14	16.4 (15.9-17.0)	17.2 (16.9-17.5)	17.3 (17.0-17.6)	17.0 (16.6-17.4)	15.8 (15.2-16.4)
	15 a 17	9.8 (9.4-10.3)	10.0 (9.8-10.2)	11.6 (11.3-11.8)	11.0 (10.6-11.3)	10.0 (9.5-10.5)
	ICD-10	Certain infectious and parasitic diseases	0.4 (0.3-0.5)	0.8 (0.7-0.9)	0.6 (0.5-0.6)	0.4 (0.3-0.5)
	Neoplasms	16.6 (16.0-17.1)	23.2 (22.9-23.5)	26.5 (26.2-26.9)	26.1 (25.6-26.7)	26.1 (25.6-26.7)
	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	3.1 (2.9-3.4)	3.7 (3.5-3.8)	5.1 (5.0-5.3)	1.3 (1.2-1.5)	1.3 (1.2-1.5)
	Endocrine, nutritional and metabolic diseases	2.3 (2.1-2.6)	2.0 (1.9-2.1)	1.6 (1.5-1.7)	1.4 (1.2-1.5)	1.4 (1.2-1.5)
	Mental and behavioral disorders	0.3 (0.2-0.4)	0.3 (0.3-0.4)	1.2 (1.1-1.3)	0.8 (0.7-0.9)	0.8 (0.7-0.9)
	Diseases of the nervous system	9.3 (8.9-9.7)	8.4 (8.2-8.6)	15.7 (15.5-16.0)	15.3 (14.8-15.7)	15.3 (14.8-15.7)
	Diseases of the circulatory system	0.8 (0.7-0.9)	0.9 (0.9-1.0)	1.7 (1.6-1.8)	1.6 (1.5-1.8)	1.6 (1.5-1.8)
	Diseases of the respiratory system	53.0 (52.3-53.8)	49.6 (49.2-50.0)	33.8 (33.4-34.1)	40.1 (39.6-40.7)	40.1 (39.6-40.7)
	Diseases of the digestive system	6.2 (5.8-6.6)	3.4 (3.2-3.5)	3.3 (3.2-3.4)	4.3 (4.0-4.5)	4.3 (4.0-4.5)
	Diseases of the genitourinary system	2.2 (1.9-2.4)	1.5 (1.5-1.6)	1.8 (1.7-1.9)	1.9 (1.7-2.0)	1.9 (1.7-2.0)
	Congenital malformations, deformations and chromosomal abnormalities	5.8 (5.4-6.1)	6.1 (5.9-6.3)	8.7 (8.5-8.9)	6.7 (6.5-7.0)	6.7 (6.5-7.0)

the nervous system is higher in Southeast, South and Middle-West and, consequently, higher by diseases of the respiratory system in North and Northeast.

## Discussion

This study reports an incidence rate of hospitalizations for children and adolescents with CCC of 331 per 100,000 inhabitants. We identified diseases of the respiratory system (asthma), neoplasms and diseases of the nervous system (epi-

lepsy and cerebral palsy and other paralytic syndromes) as the most common basic diagnosis. These findings are consistent with those reported by Berry *et al.*<sup>15</sup>, who found asthma and cerebral palsy to be among the most common primary diagnoses in the United States during 2009, with epilepsy accounting for 4.1%. In Brazil, it is possible that there is an over reporting of epilepsy as the basic diagnosis instead of cerebral palsy because of the presence of a convulsion, a symptom that is not just related to epilepsy and may mean erroneous diagnoses.

In developed countries, the prevalence of cerebral palsy ranges from 1.5 to 5.9 per 1,000 live births; the incidence in developing countries is estimated at 7.0 per 1,000 live births, characterizing a great rate. The magnitude of this issue led the Brazilian Ministry of Health to publish a document about healthcare for people with cerebral palsy<sup>16</sup>. The document is focused on pregnancy, children and childcare. Different development patterns among countries may explain the diversity of data between countries, principally related to poor primary prenatal and birth care. The severity of cerebral palsy is associated with limitations in physical activity and the presence of associated diseases. This portrayal could serve as a definition of CCC. Complexity does not relate to a single issue in the health system, as Mendes points out<sup>17</sup>. In this paper, complexity is considered as part of the subject, and complexity is incorporated by the child and in his or her health conditions.

Different to Simon *et al.*<sup>10</sup> who, using CID-9 chapters, mainly observed cardiovascular, congenital, neuromuscular, respiratory diseases and neoplasia, in decreasing order and all above 15%, we found mainly respiratory diseases (42.2%), neoplasia (24.2%), diseases of the nervous system (12.5%) and congenital malformations, deformations and chromosomal abnormalities (7.1%). Though, the difference in the proportion of causes of hospitalization among could be reflex of the health services offer, because Southeast, South and Middle-West regions are characterized as high technology centers.

The mean duration of hospitalization was six days, ranging from zero to 353. Only 13.5% of all hospitalizations required highly complex care and the mortality rate was 1.3%. This mean duration was similar to that observed by Simon *et al.*<sup>10</sup>, but the mortality rate was 10 times less. This may also be explained by the over reporting of epilepsy, leading to a decrease in related mortality rates because the prognosis of this disease is not death.

Newacheck and Kim<sup>8</sup>, studying the population aged less than 18 years in the United States, found a higher incidence among male than female patients, an increase with age, and accounting for 15.5% of this population in 2000. In the study, Simon *et al.*<sup>10</sup> also pointed to a higher rate among men and among children under the age of two years, which is consistent with our results if we group patients under two years (41.5%).

It is important to point out that there is a greater rate of hospitalizations for CCC during the first year of life, which is characterized by fast growth and skills development (motor, social, communication and cognitive). This factor, along with long-term hospitalizations or repeated admissions, may compromise the well-being of the patient and of their family. It is necessary to offer adequate hospital conditions in order to meet the specific needs of CCC patients, stimulating their growth and abilities, and to think about health promotion and damage prevention.

The main limitation of this study concerns the data source. The National Health Information System does not include data from institutions that are exclusively private, which represents 21% of total hospitalizations. This makes it possible to estimate the total number of CCC hospitalizations in the country as 240,000, which accounts for a little more than 10% of all hospitalizations among people under the age of 18 years. This estimate is close to Simon *et al.*'s<sup>10</sup> findings who identify 10.1% of under 18 years Americans as having been hospitalized for CCC in 2006. In so far, population epidemiological data in this age is available only from United States, which limits the comparability with others countries.

In 2009 in the United States, data from 400,000 patients aged below 18 years showed that 65% of hospitalizations were for CCC<sup>15</sup>, representing an increase of 13.7% since 2004.

In Brazil, this number represents less than 1% of the entire population of children and adolescents, which is all 64 million. However, the majority of hospitalizations occur due to acute episodes and not CCC. The hospital system does not make it obligatory to register secondary causes; which could allow for the identification of other CCC cases. Kuo *et al.*<sup>18</sup> analyzed combined data from 2005-06 and 2009-10 of an American national survey made by telephone interviews and found a CCC estimated prevalence of 2.7%. This survey also identified a higher proportion among men and among children under the age of six years. Considering that, Brazilian data includes just one diagnosis and often the hospitalization

of CCC patients occurs because of an acute episode, the population prevalence is expected to be greater than 1%.

Regarding hospitalization data in Brazil, the South region presents the highest rate and the North region the lowest. This may reflect access to specialized health services, because the most developed hospitals are found in the South, which also has the highest rate of life expectancy in the country<sup>19</sup>.

Other limitations include diagnosis mistakes, repeated hospitalizations and patient transfers that are not identified by the hospital system, as well as the selective morbidity caused by a single diagnosis. Nevertheless, it is important to use the hospital database system in order to quantify hospitalizations and to point to the fragility of the system in order to improve the registration of data including the CID's secondary and associated diagnoses.

In spite of these limitations, this study was the first in Brazil that has sought to estimate the magnitude of CCC. The use of recent data avoids helps to avoid many diagnoses mistakes because of improvements in hospital performance during this time. This makes it possible to establish a CCC baseline in Brazil, but it is not possible to identify trends because there is no estimate of the number of mistaken diagnoses over the time.

The use of rates makes it possible to compare groups, and the proportion shows the size of each group in the country. This can support decisions on resource allocation according to the respective proportion, which is greater in the Northeast and Southeast, for example. It is important to highlight the exploratory character of this study and to point out the need of more detailed hospitalization data, including secondary diagnosis of hospitalization.

Indeed, at least 240,000 children and adolescents are hospitalized each year, representing an important proportion of the overall hospital population, thereby making this an important emerging public health issue in Brazil. In this way, the situation of children and adolescents with CCC calls for a "new pediatrics" in Brazil<sup>20</sup> with diversified professional resources and technology, with the preparation of a specific health plan and program that is consistent with the National Health Policy and aims to provide adequate and comprehensive care to all children and adolescents with CCC<sup>21</sup>. Nonetheless, more studies are necessary in order to identify the true dimension of CCC in Brazil, besides to compare the evolution throughout the time.

## Collaborations

EC Moura: substantial contributions to conception and design, acquisition, analysis and interpretation of data, drafting the article; MCN Moreira: substantial contributions to conception, interpretation of data, critical revision, drafting the article; LA Menezes: substantial contributions to conception, critical revision, interpretation of data, final approval; IA Ferreira: acquisition of data, critical revision, final approval; R Gomes: interpretation of data, critical revision, final approval.

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