Jornal de Pediatria 2022;98(5): 484—489

Jornal de Pediatria
www.jped.com.br

ORIGINAL ARTICLE

Prevalence and functional status of children with complex chronic conditions in Brazilian PICUs during the COVID-19 pandemic

José Colleti Junior [a,b,*], Arnaldo Prata-Barbosa [c], Fernanda Lima-Setta [c], Orlei Ribeiro de Araujo [d], Nelson K. Horigoshi [e], Regina Grigolli Cesar [e], Andreia Aparecida Freitas Souza [e], Flávia Andrea Krepel Foronda [f], Carlos Gustavo de Almeida [a], Lara de Araujo Torreão [g], Francielly Crestani [h], Ana Paula de Carvalho Panzeri Carlotti [i,j], Pedro Celiny Ramos Garcia [h], on behalf of the Brazilian Research in Intensive Care (BRICnet)

[a] *Hospital Assunção Rede D'Or São Luiz, São Bernardo do Campo, SP, Brazil*
[b] *Hospital Alvorada Moema, São Paulo, SP, Brazil*
[c] *Instituto D'Or de Pesquisa e Ensino (IDOR), Rio de Janeiro, RJ, Brazil*
[d] *Instituto de Oncologia Pediátrica (GRAACC), São Paulo, SP, Brazil*
[e] *Hospital Infantil Sabará, São Paulo, SP, Brazil*
[f] *Hospital Sírio-Libanês, São Paulo, SP, Brazil*
[g] *Hospital Aliança, Salvador, BA, Brazil*
[h] *Pontifícia Universidade Católica do Rio Grande do Sul, Porto Alegre, RS, Brazil*
[i] *Universidade de São Paulo, Faculdade de Medicina de Ribeirão Preto, Hospital das Clínicas, Ribeirão Preto, SP, Brazil*
[j] *Faculdade de Medicina de Ribeirão Preto, Unidade de Emergência, Ribeirão Preto, SP, Brazil*

Received 7 July 2021; accepted 8 December 2021
Available online 31 December 2021

KEYWORDS
Chronic disease;
Functional status;
Critical care;
Pediatrics;
COVID-19;
Cross-sectional studies

Abstract

Objective: The proportion of children with complex chronic conditions is increasing in PICUs around the world. We determined the prevalence and functional status of children with complex chronic conditions in Brazilian PICUs during the COVID-19 pandemic.

Methods: The authors conducted a point prevalence cross-sectional study among fifteen Brazilian PICUs during the COVID-19 pandemic. The authors enrolled all children admitted to the participating PICUs with complex chronic conditions on three different days, four weeks apart, starting on April 4th, 2020. The authors recorded the patient's characteristics and functional status at admission and discharge days.

Study conducted at Hospital Assunção, Hospital Santa Catarina, Hospital Infantil Sabará, Hospital Sírio-Libanês, Hospital das Clínicas da FMRP-USP, Unidade de Emergência da FMRP-USP, Hospital Copa D'Or, Hospital Rios D'Or, Hospital Caxias D'Or, Hospital Quinta D'Or, Hospital Real D'Or, Hospital Oeste D'Or, Hospital da Criança, Hospital Aliança, Hospital São Lucas da PUCRS.

* Corresponding author.
E-mail: colleti@gmail.com (J. Colleti).

https://doi.org/10.1016/j.jped.2021.12.004

Results: During the 3 study days from March to June 2020, the authors enrolled 248 patients admitted to the 15 PICUs; 148 had CCC (prevalence of 59.7%). Patients had a median of 1 acute diagnosis and 2 chronic diagnoses. The use of resources/devices was extensive. The main mode of respiratory support was conventional mechanical ventilation. Most patients had a peripherally inserted central catheter (63.1%), followed by a central venous line (52.5%), and 33.3% had gastrostomy or/and tracheostomy. The functional status score was significantly better at discharge compared to admission day due to the respiratory status improvement.
Conclusions: The prevalence of children with CCC admitted to the Brazilian PICUs represented 59.7% of patients during the COVID-19 pandemic. The functional status of these children improved during hospitalization, mainly due to the respiratory component.

Introduction

Children with complex chronic conditions (CCC) was defined by Feudtner 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".[1] The proportion of children with chronic diseases and/or disabilities is increasing, being up to 50% in some pediatric hospitals.[2,3] Due to advances in intensive care, there has been a reduction in mortality, but at the expense of immobility, longer mechanical ventilation, and increased use of hospital resources.[4–6] The use of drugs such as corticosteroids, neuromuscular blockers, and sedatives increased the risk of physical and neurocognitive sequelae.[7] These children may develop muscle weakness and delirium as well as decreased functionality and difficulties in activities of daily living, school performance, and social interaction.[8,9] For this reason, interest in the functional outcomes of this population is growing.

The overall proportionate distribution of PICU resources among children with medical complexity, however, is unclear and has not been delineated previously in Brazil. Describing the distribution of critical care resources, stratified by medical complexity, is an important first step in optimizing critical care use among all patient groups, but specifically, those with CCC, to build policies and guidelines. To date, no studies in Brazil reported the prevalence or functional status of patients with CCC in PICUs. The authors know that the COVID-19 pandemic reduced admissions due to respiratory causes to PICUs.[10,11] However, we do not know if patients with CCC were also affected. This study aimed to determine the prevalence and functional status of children with CCC in Brazilian PICUs during the COVID-19 pandemic.

Methods

Design

This was a point-prevalence, cross-sectional study. A convenience sample was chosen among members of the Brazilian Research in Intensive Care (BRICnet), and an invitation was sent by email. The authors surveyed data of children treated in 15 PICUs of different parts of Brazil that accepted to participate in the study, which was approved by the Institutional Review Board of each participating center.

The authors collected data of inpatients in the participating PICUs at 9 AM on three different days, four weeks apart, starting on April 4th, 2020. The second study day was June 2nd, 2020, and the last study day was July 28th, 2020. Study data were collected and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at Instituto D'Or de Ensino e Pesquisa (IDOR). REDCap is a secure, web-based application designed to support data capture for research studies.[12] The inclusion criteria were any patient in the PICU in the study day who met the criteria for CCC according to Feudtner's definition,[1] and had a written consent form. Patients were excluded if parents/guardians did not give consent to use data.

The first form was designed to collect data from the participating hospitals and PICUs, such as the number of beds, characteristics (private/public), number of healthcare professionals. The second form was a screening log to provide the prevalence of patients with CCC. The total number of patients and patients with CCC was recorded. The final form was related to the patient's characteristics, demographics, the acute reason for admission, chronic conditions, length of stay, respiratory support, use of devices, use of PICU resources, and 90-day outcome. The authors also determined the functional status of patients at admission, on the study days, and at discharge using the Functional Status Scale (FSS) that has six components (mental status, sensory functioning, communication, motor functioning, feeding, and respiratory status) and scores from 6 (higher functional status) to 30 (lower functional status).[13]

Statistical analysis

The frequencies were described in percentages and absolute numbers, means, and standard deviation or medians and interquartile intervals, as appropriate. For comparisons between averages, the *t*-test was used. For survival analysis, the authors used the Kaplan Meier curves and the log-rank test. Logistic regression was used to analyze the association between the functional scale and the risk of death. The analysis was performed using R software (R Foundation for Statistical Computing, Vienna, Austria).

Results

Fifteen PICUs participated in the study, 7 from Rio de Janeiro State, 6 from São Paulo State, 1 from Bahia State, and 1 from the Rio Grande do Sul State. During the 3 study days, the authors enrolled 248 patients admitted to the 15 PICUs, 148 of whom had CCC (59.7%). Seven subjects were excluded for the lack of the consent form. Most PICUs were from private hospitals, hosting between 101 and 300 beds (73.3%). The number of PICU beds ranged from 4 to 36 with a median of 10 (IQ, 8–13). All PICUs had 24/7 pediatric intensive care attending physicians. The main participating PICUs characteristics are shown in Supplementary material.

The median age of patients was 23.2 (IQ, 7.5–58.4), with an important difference in the length of stay between survivors (26 days; IQ, 9–65) and deceased (96 days; IQ, 38.5–504.2). Most patients were admitted from the Emergency Room (48%) and were discharged to the ward (43.6%). The demographic data of patients with CCC are shown in Table 1.

The authors also recorded the acute diagnosis at admission and the chronic diagnosis of patients with CCC, which are shown in Table 2. The most prevalent acute diagnosis was acute respiratory distress (14.2%), followed by postoperative patients (except transplants) with 12.1%. The most prevalent chronic diagnosis was severe neurological impairment (16%), followed by genetic syndromes (14.7%).

Table 1 Characteristics of patients with CCC admitted to the PICUs.

N	141
Feminine	57 (40%)
Age in months (median, IQ)	23.2 (7.5-58.4)
Death N (%)	11 (7.8%)
Length of stay (survivors) median (IQ)	26 (9-65)
Length of stay (deceased) median (IQ)	96 (38.5-504.2)
Race/Ethnic group	
Caucasian	75%
Black	6.4%
Multiracial	17.8%
Asian	0.8%
Admission origin	
Emergency Room	48%
Neonatal ICU	5%
Operating Room	12%
Home Care	4%
Ward	11%
Day Hospital	1%
Other Hospital	19%
Discharge (N, %)	
Home	38 (30.2%)
Ward	55 (43.6%)
Step Down Unit	1 (0.8%)
Day Hospital	1 (0.8%)
Other	31 (24.6%)

CCC, Complex Chronic Conditions.

Table 2 Acute/Chronic diagnosis of patients with CCC at admission.

Number of acute diagnosis (median, range)	1 (1–4)	
Number of chronic diagnosis (median, range)	2 (1–4)	
Acute diagnosis (N, %)		
Acute respiratory distress	20	14.2%
Pneumonia	11	7.8%
Sepsis/septic shock	6	4.2%
Postoperative, except transplants	17	12.1%
Postoperative, hepatic/renal transplant	7	5%
Covid-19	5	3.5%
UTI	3	2.1%
Ventriculitis	2	1.4%
Seizure	9	6.4%
Other	61	43.3%
CCC		
Genetic Syndrome	22	14.7%
CNS malformation	17	11.3%
Severe neurological impairment	24	16%
Cardiopathy/Cardiac malformation	15	10%
Prematurity	13	8.7%
Chronic lung disease of prematurity	6	4%
Epilepsy/ Epileptic syndrome	20	13.3%
Biliary atresia	5	3.3%
Neoplasia	13	8.7%
Asthma	4	2.7%
Chronic renal failure	11	7.3%

CCC, Complex Chronic Conditions; UTI, Urinary Tract Infection; CNS, Central Nervous System.

The authors collected data on the devices and resources used by patients with CCC, showing that 36.9% were on conventional mechanical ventilation, while 36.2% did not need any respiratory support; 63.1% had a peripherally inserted central catheter (PICC), and 52.5% had a central venous line, and 33.3% of patients had tracheostomy and gastrostomy (Table 3).

The functional status of patients with CCC was compared at admission and on discharge day using the FSS scale, showing an improvement in the final score due to the respiratory component of the scale (Table 4).

Discussion

This study addressed the prevalence of patients with CCC in Brazilian PICUs during the COVID-19 pandemic. There has been a paucity of data on the prevalence of patients with CCC in Brazilian PICUs, and this study is the first to tackle this topic during the COVID-19 pandemic. The authors found a prevalence of 59.7% of patients with CCC among 15 PICUs. It is important to consider that the study was conducted during the COVID-19 pandemic when the admissions in Brazilian PICUs reduced significantly.[10] Hence, it may not represent the true prevalence of CCC in Brazilian ICUs during non-

Table 3 Clinical resources and devices of patients with CCC.

Respiratory support	N	%
Ambient air	51	36.2%
Oxygen (nebulization, nasal catheter, etc.)	7	5.0%
High-Flow Nasal Cannula	6	4.3%
CPAP	3	2.1%
BiPAP	11	7.8%
Other noninvasive support	5	3.5%
Conventional Mechanical Ventilation	52	36.9%
High-Frequency Oscillatory Ventilation	2	1.4%
Other	4	2.8%
Venous line		
Venoclisis	66	46.8%
PICC	89	63.1%
Central venous line	74	52.5%
Port-a-cath	12	8.5%
None	22	15.6%
Other	12	8.5%
Other		
Gastrostomy	47	33.3%
Jejunostomy/Colostomy/Ileostomy	10	7.1%
Ventriculoperitoneal shunt	13	9.2%
Tracheostomy	47	33.3%
Endotracheal tube	17	12.1%
Intermittent urinary catheter	2	1.4%
Indwelling urinary catheter	28	19.9%
Arterial line	7	5.0%
Atrial catheter	1	0.7%
Nasogastric/enteric tube	21	14.9%
Other	34	24.1%

CCC, Complex Chronic Conditions; PICC, peripherally-inserted central catheter.
The sum of the percentages is greater than 100% because many patients had more than one device.

pandemic years. The authors cannot determine how much the COVID-19 pandemic impacted that prevalence. A study in public hospitals in Brazil reports an incidence rate of hospitalizations for children and adolescents with CCC of 331 per 100,000 inhabitants.[14] A large study in the USA with 54 PICUs reported that 53% of the patients admitted had a CCC.[3] Another study with 35 USA PICUs that used the Virtual Pediatric Systems (VPS) reported 52.1% of patients with the chronic diagnosis.[15] In Canada, children, and youth with CCC accounted for 37% of all hospital admissions and 54% of total hospital days.[16] They also had longer stays compared with children and youth without medical complexity. A French study reported a prevalence of 67% of patients with chronic conditions among 23 PICUs.[17] A study in Argentina showed a prevalence of 48.06% of patients with CCC in 19 PICUs. Unlike ours, all such studies were conducted before the COVID-19 pandemic. The authors know that admissions for respiratory diseases were reduced and surgeries canceled during the pandemic, many of which in CCC patients.[10,11,18] But the authors still do not know the real impact on the overall prevalence of CCC patients in the PICU.

According to many studies, within hospitals, and specifically PICUs, children with chronic illnesses represent an increasing proportion of the population and an important financial burden of healthcare utilization.[3,5,19] The increasing trend of occupation of PICU beds and ventilator days by critically ill children may be related to the increasing trend or hospitalization of chronic care patients.[20] Table 3 shows the use of clinical resources, including respiratory support, venous line, and other devices. In the present study, the most frequently used venous line was PICC (31.9%), followed by a central venous line (27%), and the main mode of respiratory support was conventional mechanical ventilation (36.9%). The extensive use of resources/devices observed in the present study is in line with the literature that reports that there is disproportionate usage of ICU resources and therapies by children with medical complexity.[21] These findings are important to guide better healthcare public policies regarding children with CCC.

Most patients were discharged from the PICU to the ward (43.6%), followed by home (30.2%), which is a common practice in Brazil, mainly in private hospitals, for reasons related to the Private Healthcare System policies.

The authors were able to determine the mortality rate of these patients in a 90 days follow-up (7.8%), which is higher than 2 studies from the USA (3.9% and 3.7%),[3,15] and another study from Canada (2%).[16] The authors do not know for sure why the mortality is higher in Brazil; however, the authors know that palliative care in children at home in Brazil is still incipient and many children who should be receiving palliative care at home still dye in the PICU. That could partly explain the length of stay difference between survivors and

Table 4 FSS at admission and discharge days.

	Admission		Discharge		
	Mean	(SD)	Mean	(SD)	p[a]
Mental Status	2.3	(1.3)	1.8	(1.1)	0.15
Sensory Functioning	2.0	(1.3)	1.6	(1.1)	0.12
Communication	2.6	(1.6)	2.0	(1.2)	0.07
Motor Functioning	2.7	(1.5)	2.3	(1.5)	0.35
Feeding	2.4	(1.1)	2.2	(1.1)	0.11
Respiratory Status	2.9	(1.8)	2.2	(1.6)	**0.001**
FSS	14.9	(7.1)	12.0	(6.4)	**0.001**

[a] Paired *t*-test.
SD, Standard deviation.

the deceased. Although it was not the aim of this study, the authors have to highlight that the lack of a palliative care group could have contributed to reducing the length of stay and costs related to terminally ill patients.

The authors determined the functional status of patients using the FSS score, which has been validated in Brazil.[22,23] Interestingly, the FSS score improved at discharge compared to the admission day (mean 14.9 vs. 12, p = 0,001), mainly because of improvement in the respiratory component of the FSS score (p = 0.001). The respiratory status at discharge significantly improved compared to admission (median 2.2 vs. 2.9, p = 0.001). The other components of the FSS did not significantly change. Although the FSS improvement was due to the improvement in respiratory status, only 22% of admissions were related to respiratory causes. It is counter-intuitive to find a better functional status at discharge, but the authors believe that the respiratory condition of these patients is so relevant that as soon as the patient's clinical condition improves, they improve the overall functional status. The mean FSS of patients was considered moderately abnormal, according to Pollack.[13] Pollack et al. studied the functional status in 8 PICUs and found that the overall FSS increased at discharge compared to the baseline.[7] The FSS ranges from 6 to 30, and the means of 12 at admission and 14.9 at discharge. These scores represent a moderate abnormal functional status. Few studies are reporting the functional status of children during PICU stay in Brazil. A study by Pereira GA et al. evaluated the functional status using the FSS and reported moderate impairment in pediatric patients in general after discharge from the pediatric intensive care unit, mainly in the "motor function" and "feeding" domains.[23]

The present study has some limitations. Although it is a cross-sectional multicenter study, it may not reflect the reality of all Brazilian PICUs as it was a convenience sampling including 15 non-randomized PICUs. Moreover, the participating centers are mainly from private hospitals of the most developed regions of Brazil and may not represent the reality of other Brazilian PICUs. Since there are no previous reports of the prevalence of patients with CCC in Brazilian PICUs, the authors do not know how much the COVID-19 pandemic affected the present study's results, as we are unable to compare.

Albeit it was performed during the COVID-19 pandemic surge, and despite its limitations, this is the first multicenter study to determine the prevalence and functional status of children with CCC in Brazilian PICUs. The present study's findings on patients' characteristics and resource utilization may contribute to better planning of care provided to critically ill children with CCC. Future studies should address the impact of CCC on the development, social integration, family role, and health resources use of these patients. Therefore, we can build guidelines, public policies, and strategies to promote better care for these patients and their families. The authors should also study the prevalence of CCC patients in the post-COVID-19 era to better understand its impact on those patients.

The prevalence of children with CCC admitted to the Brazilian PICUs during the COVID-19 pandemic was higher (59.7%) than previous studies in other countries performed outside the pandemic context. The functional status of these children improved during hospitalization, mainly due to the respiratory component. The CCC population uses significant resources in PICU with prolonged PICU stay. This study may help understand the needs of this population in Brazilian PICUs and to build guidelines and public policies.

Conflicts of interest

The authors declare no conflicts of interest.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jped.2021.12.004.

References

1. Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. BMC Pediatr. 2014;14:199.
2. Arias López MD, Fernández AL, Fiquepron K, Meregalli C, Ratto ME, Siaba Serrate A, et al. Prevalence of children with complex chronic conditions in PICUs of Argentina: a prospective multicenter study*. Pediatr Crit Care Med. 2020;21:e143–51.
3. Edwards JD, Houtrow AJ, Vasilevskis EE, Rehm RS, Markovitz BP, Graham RJ, et al. Chronic conditions among children admitted to US pediatric intensive care units: their prevalence and impact on risk for mortality and prolonged length of stay*. Crit Care Med. 2012;40:2196–203.
4. Russell Christopher J, Simon Tamara D. Care of Children with medical complexity in the hospital setting. Pediatr Ann. 2014;43:e157–62.
5. Murphy Salem S, Graham RJ. Chronic illness in pediatric critical care. Front Pediatr. 2021;9:686206.
6. Silber JH, Rosenbaum PR, Pimentel SD, Calhoun S, Wang W, Sharpe JE, et al. Comparing resource use in medical admissions of children with complex chronic Conditions. Med Care. 2019;57:615–24.
7. Pollack MM, Holubkov R, Funai T, Clark A, Berger JT, Meert K, et al. Pediatric intensive care outcomes: development of new morbidities during pediatric critical care. Pediatr Crit Care Med. 2014;15:821–7.
8. Kasinathan A, Sharawat IK, Singhi P, Jayashree M, Sahu JK, Sankhyan N. Intensive care unit–acquired weakness in children: a prospective observational study using simplified serial electrophysiological testing (PEDCIMP Study). Neurocrit Care. 2020;7:1–8.
9. Colleti JJ, de Carvalho WB. PICU-acquired weakness: underestimated and underreported. Pediatr Crit Care Med. 2016;17:381.
10. Araujo OR, Almeida CG, Lima-Setta F, Prata-Barbosa A, J Colleti Junior. Brazilian Research Network in Pediatric Intensive Care (BRnet-PIC). The impact of the novel coronavirus on Brazilian PICUs. Pediatr Crit Care Med. 2020;21:1059–63.
11. Vásquez-Hoyos P, Diaz-Rubio F, Monteverde-Fernandez N, Jaramillo-Bustamante JC, Carvajal C, Serra A, et al. Reduced PICU respiratory admissions during COVID-19. Arch Dis Child. 2020. archdischild-2020-320469.
12. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42:377–81.

13. Pollack MM, Holubkov R, Glass P, Dean JM, Meert KL, Zimmerman J, et al. The functional status score (FSS): A new pediatric outcome measure. Pediatrics. 2009;124:e18—28.
14. Moura EC, Moreira MC, Menezes LA, Ferreira IA, Gomes R. Complex chronic conditions in children and adolescents: hospitalizations in Brazil, 2013. Cien Saude Colet. 2017;22:2727—34.
15. Typpo KV, Petersen NJ, Petersen LA, Mariscalco MM. Children with chronic illness return to their baseline functional status after organ dysfunction on the first day of admission in the Pediatric Intensive Care Unit. J Pediatr. 2010;157:108—13. e1.
16. Canadian Institute for Health Information. Children and youth with medical complexity in Canada. Ottawa, ON: CIHI; 2020.
17. Cremer R, Leclerc F, Lacroix J, Ploin D. Children with chronic conditions in pediatric intensive care units located in predominantly French-speaking regions: Prevalence and implications on rehabilitation care need and utilization*. Crit Care Med. 2009;37:1456—62.
18. COVIDSurg Collaborative. Elective surgery cancellations due to the COVID-19 pandemic: global predictive modelling to inform surgical recovery plans. Br J Surg. 2020;107:1440—9.
19. Crow SS, Undavalli C, Warner DO, Katusic SK, Kandel P, Murphy SL, et al. Epidemiology of pediatric critical illness in a population-based birth cohort in Olmsted County, MN. Pediatr Crit Care Med. 2017;18:e137—45.
20. Briassoulis G, Filippou O, Natsi L, Mavrikiou M, Hatzis T. Acute and chronic paediatric intensive care patients: current trends and perspectives on resource utilization. QJM. 2004;97:507—18.
21. Chan T, Rodean J, Richardson T, Farris RW, Bratton SL, Di Gennaro JL, et al. Pediatric critical care resource use by children with medical complexity. J Pediatr. 2016;177:197—203. e1.
22. Bastos VC de S, Carneiro AAL, Barbosa M dos SR, Andrade LB de. Brazilian version of the Pediatric Functional Status Scale: translation and cross-cultural adaptation. Rev Bras Ter Intensiva. 2018;30:301—7.
23. Pereira GA, Schaan CW, Ferrari RS, Normann TC, Rosa NV, Ricachinevsky CP, et al. Functional status scale: cross-cultural adaptation and validation in Brazil. Pediatr Crit Care Med. 2019;20:e457—63.