

BRIEF REPORT

Point Prevalence of Children Hospitalized With Chronic Critical Illness in the General Inpatient Units

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ABSTRACT

OBJECTIVES: Children with medical complexity (CMC) have high rates of mortality and morbidity, prolonged lengths of stay, and use a disproportionately high amount of health care expenditures. A subset of children with CMC have chronic critical illness requiring even higher levels of clinical support and resource use. We aimed to describe the point prevalence of children hospitalized in general inpatient care units with pediatric chronic critical illness (PCCI).

METHODS: Point prevalence analysis across 6 pediatric tertiary medical centers in the United States on a “snapshot day” (May 17, 2017). On the day of sampling, a number of demographic, historical, and clinical descriptors were collected. A previously published definition of PCCI was used to establish inclusion criteria.

RESULTS: The point prevalence of patients with PCCI in general inpatient care units was 41% (232 out of 571). Of these, 91% (212 out of 232) had been admitted more than once in the previous 12 months, 50% (117 out of 232) had a readmission within 30 days of a previous admission, and 20% (46 out of 232) were oncology patients. Only 1 had a designated complex care team, and there were no attending physicians designated primarily for medically complex children.

CONCLUSIONS: Children with chronic critical illness, a subset of CMC, may make up a substantial proportion of pediatric patients hospitalized in general inpatient care units. There is a critical need to understand how to better care for this medically fragile population. In our data, it is suggested that resources should be allocated for PCCI in nonintensive care clinical areas.

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Chronic critical illness (CCI) is a term described in adult literature to depict patients who survive acute critical illness but are unable to return to their previous state of health.¹⁻³ Patients with CCI often suffer multiorgan dysfunction, are dependent on medical technology, and are highly resource intensive.^{2,3} Recently, the term CCI has been applied to the pediatric population as pediatric chronic critical illness (PCCI).⁴ Although there are limited published reports on PCCI, an increase in medical complexity has been linked to an increased frequency of multiple ICU admissions,⁵ hospitalization rates,⁵⁻⁷ and significant inpatient resource use.⁷⁻¹¹

It may be difficult for hospitals to proportionately allocate resources without a clear understanding of where high-resource-intensive pediatric patients are cared for within the hospital (eg, general care floors, PICUs, NICUs, etc). Although children with medical complexity (CMC) have been found to represent more than half of pediatric intensive care admissions,^{4,5,12,13} our objective was to determine the point prevalence of PCCI on the general pediatric floors of 6 pediatric hospitals in the United States in patients not being cared for in the ICU setting.

METHODS

Data were obtained on a single date, May 17, 2017, from a collaborative composed of 6 tertiary care pediatric referral centers experienced in the care of pediatric patients with complex illness. The date was mutually agreed on by investigators at all sites. Two centers were freestanding children's hospitals, and 4 were embedded in university medical centers. Medical records of all children, except those hospitalized in psychiatric units, were screened on the study day to determine if they met the definition of PCCI, which was defined as a patient who, for the current hospitalization, (1) had been hospitalized in the NICU until 44 weeks' postmenstrual age, spent >14 consecutive days in the PICU, had ≥ 2 hospitalizations in the past 12 months, or had been hospitalized for >180 days and (2) had ongoing dependence on technology (defined as tracheostomy, mechanical ventilation, any oxygen delivery system,

surgical or nonsurgical feeding tubes, indwelling catheters, central lines, need for dialysis, intracranial shunts, history of organ or bone marrow transplant, or multiple organ system involvement [defined as a chronic medical problem in ≥ 2 organ systems that has already lasted, or was expected to last, >3 months]).⁴

Clinical Data

On the study day, hospitalized patients meeting PCCI criteria were identified. Patient variables for the current admission, including the number of hospitalizations over the previous 12 months (including the current admission), were recorded. Patients were labeled as oncologic if they had an active malignancy or sequelae of malignancy as the primary admitting diagnosis. Side-by-side comparison of oncologic and non-oncologic patients meeting criteria for PCCI on the general care floors were also investigated. Trained research assistants reviewed individual charts using a standardized tool for data collection.

Center Characteristics

The 6 referral centers provided self-reported data, such as a designated complex care team, complex care unit, distinction of general care from step-down units, and primary attending physicians for PCCI.

Data Analysis

The primary outcome assessed was the point prevalence of PCCI on inpatient (non-ICU) units across all 6 referral centers. This was obtained by calculating the number of children who met PCCI criteria in the general care units divided by the total number of patients hospitalized in the general care units on the study day. General care floors were distinguished from step-down units, and patients hospitalized in step-down units were excluded. Descriptive statistics characterized the study population; nonparametric statistics were used for between-group comparisons. A *P* value <.05 was considered statistically significant.

RESULTS

Point prevalence of patients meeting PCCI criteria not admitted to the ICU setting was

41% of the total general care unit census (232 out of 571) for the 6 centers. Of these, 80% (186 out of 232) were nononcologic patients. One of the 6 centers reported having a complex care team, and none reported having dedicated complex care attending physicians. No child was hospitalized in a step-down unit.

Of all general floor patients with PCCI, 1% (2 out of 232) was hospitalized in the NICU until >44 weeks' gestational age, 6% (14 out of 232) had a PICU stay longer than 14 days, 91% (212 out of 232) had been admitted at least twice (range: 2-26 hospitalizations) in the previous 12 months, and 4% (10 out of 232) had a length of stay >180 days. Additionally, 52% (120 out of 232) required ≥ 2 technology assistive devices, 93% (216 out of 232) had >1 organ system involved, and 50% (117 out of 232) had a previous hospitalization within 30 days of the current hospitalization. Significant differences were noted between nononcologic PCCI and oncologic PCCI with regards to time spent in the ICU, previous hospitalization within 30 days of the current hospitalization, use of ventilator support, number of systems affected, planned versus unplanned hospitalization, and number of current technologies. In Table 1, we describe additional characteristics of non-ICU patients with PCCI.

Of the current technologies, more than half (56%) of patients with PCCI required the use of feeding tubes, the majority of which were surgically placed (37%). Other specific technologies included central venous catheters (47%), cranial shunts (7%), and respiratory support (30%) such as tracheostomies (11%) and ventilator or continuous or bilevel positive airway pressure support (10%). In this population, the most frequent chronically affected systems were gastrointestinal (69%), hematologic (43%), pulmonary (40%), and neurologic (38%).

DISCUSSION

We found that on 1 day, chosen at random, roughly 40% of the children in the general care units at 6 pediatric referral hospitals met criteria for PCCI. The criteria allow for identification of highly resource-intensive

TABLE 1 Characteristics of Non-ICU PCCI With and Without Oncologic Disease

Variables	Floor (n = 186), n (%)	Oncology (n = 46), n (%)	P	Total PCCI (n = 232), n (%)
Age			.13	
<12 mo	36 (19)	2 (4)		38 (16)
1–5 y	57 (31)	19 (41)		76 (33)
6–10 y	26 (14)	5 (11)		31 (13)
11–15 y	33 (18)	10 (22)		43 (19)
≥16 y	34 (18)	10 (22)		44 (19)
Race and ethnicity			.22	
White	84 (45)	22 (48)		106 (46)
African American	49 (26)	8 (17)		57 (25)
Asian American	8 (4)	2 (4)		10 (4)
Hispanic	22 (12)	11 (24)		33 (14)
Other	8 (4)	2 (4)		10 (4)
Not recorded	15 (8)	1 (2)		16 (7)
Sex			.40	
Male	106 (57)	30 (65)		136 (57)
Female	80 (43)	16 (35)		96 (41)
No. admissions in last 12 mo ^a			.24	
1	19 (10)	1 (2)		20 (9)
2	55 (30)	12 (26)		67 (29)
3	34 (18)	8 (17)		42 (18)
4+	78 (42)	25 (54)		103 (44)
Previous hospitalization within 30 d of current hospitalization	80 (43)	37 (80)	<.01	119 (51)
Current hospitalization planned	40 (22)	40 (87)	<.01	80 (35)
Any time in ICU this hospitalization	67 (36)	5 (11)	<.01	72 (31)
Any time on mechanical ventilation this admission	70 (38)	6 (13)	<.01	76 (33)
No. current technologies			<.01	
0	26 (14)	0		26 (11)
1	62 (33)	24 (52)		86 (37)
2+	98 (53)	22 (48)		120 (52)
No. systems affected			<.01	
1	10 (5)	6 (13)		16 (7)
2	27 (15)	10 (22)		37 (16)
3	31 (17)	2 (4)		33 (14)
4+	118 (63)	28 (61)		146 (63)
No. procedures this admission			.25	
0	113 (61)	31 (67)		144 (62)
1–3	51 (27)	14 (30)		65 (28)
4+	22 (12)	1 (2)		23 (10)
No. surgeries this admission			.31	
0	122 (66)	40 (87)		162 (70)
1–3	56 (30)	5 (11)		61 (26)
4+	5 (3)	1 (2)		6 (3)
No. active medications this admission ^b			.53	
1–2	12 (7)	1 (2)		13 (6)
3–5	38 (20)	11 (24)		49 (21)

patients at varying stages of illness, both in the ICU and on the general care floors. Thus, we suggest that hospitalized children who meet the definition of PCCI comprise a substantial portion of patients in general care pediatric units, despite their frequent intensive care needs and varying markers of severity.

In previous studies, it has been shown that children with multiple complex chronic conditions compared with children with no complex chronic conditions have up to threefold longer hospital length of stay, 11-fold increase in hospital charges, and a 15-fold increase of risk of inpatient death.⁷ Of all patients who met criteria for PCCI in this analysis, 91% had been admitted at least twice in the previous 12 months, and 52% required ≥2 technology assistive devices.

Understanding the point prevalence of PCCI on the general care floors is helpful, considering CMC comprise <1% of the pediatric population¹⁰ yet account for one-third of child health spending,^{10,14} 80% of which is related to inpatient care.^{15,16} Special consideration should be made to the differences in unit capabilities where these patients are hospitalized (eg, ICU versus general floor setting) in conjunction with patient needs. Presumably, ICUs have a higher level of staffing, resources, and technology and respiratory support than the general care units. In our study, we also specifically present data regarding the subset of children with PCCI who do not have an oncologic diagnosis. Children with oncologic processes often have dedicated care teams or additional inpatient and/or outpatient resources beyond what may be available to other children hospitalized with PCCI.

Designated inpatient complex care teams and complex care coordination efforts seek to improve health outcomes between multiple providers, polypharmacy, and subspecialty involvement.^{17–21} Only 1 of the 6 hospitals in our study had a designated complex care team, and no hospital had designated attending physicians for medically complex children. As the number of children with medical complexities continues to rise, the need to learn how to provide optimal care for this delicate

TABLE 1 Continued

Variables	Floor (n = 186), n (%)	Oncology (n = 46), n (%)	P	Total PCCI (n = 232), n (%)
6–8	41 (22)	14 (30)		55 (24)
9+	95 (51)	20 (43)		115 (50)

^a Includes current admission.

^b Excludes “take as needed” medications.

patient population is paramount. Although we did not determine which specialty was caring for patients with PCCI in this study, pediatric hospital medicine is considered an ideal field to manage complex care.^{18,22} Future research on how to best allocate resources to the general care services that are caring for a large percentage of PCCI may be necessary.

LIMITATIONS

Our study has limitations. First, the participating sites were all tertiary care medical centers, limiting the generalizability to smaller institutions or community-based hospitals. Second, there is likely variability among hospitals in terms of criteria for bed placement or ability to care for certain pediatric populations on general care floors rather than the ICU (eg, ventilator-supported patients). Third, our study day represents 1 chosen date, and an analysis performed on a different date or in a different season may yield different results, especially if patients with PCCI transfer to and from the ICU setting throughout an admission. And fourth, it is possible that patients who do not meet PCCI criteria require high levels of use, which may serve to underestimate the true resource need in the general care units.

CONCLUSIONS

We identified a substantial proportion of patients in the general care units who met criteria for PCCI. In future studies, researchers should provide a more-detailed examination of this population and examine whether this trend holds true in other facilities. This would allow hospitals to better allocate resources and optimize care for CMC and CCI.

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REFERENCES

1. Kahn JM, Le T, Angus DC, et al; ProVent Study Group Investigators. The epidemiology of chronic critical illness in the United States*. *Crit Care Med*. 2015;43(2):282–287
2. Nelson JE, Cox CE, Hope AA, Carson SS. Chronic critical illness. *Am J Respir Crit Care Med*. 2010;182(4):446–454
3. Marchioni A, Fantini R, Antenora F, Cline E, Fabbri L. Chronic critical illness: the price of survival. *Eur J Clin Invest*. 2015; 45(12):1341–1349
4. Shapiro MC, Henderson CM, Hutton N, Boss RD. Defining pediatric chronic critical illness for clinical care, research, and policy. *Hosp Pediatr*. 2017; 7(4):236–244
5. Chan T, Rodean J, Richardson T, et al. Pediatric critical care resource use by children with medical complexity. *J Pediatr*. 2016;177:197–203.e1
6. Burns KH, Casey PH, Lyle RE, Bird TM, Fussell JJ, Robbins JM. Increasing prevalence of medically complex children in US hospitals. *Pediatrics*. 2010;126(4):638–646
7. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics*. 2010; 126(4):647–655
8. Berry JG, Agrawal R, Kuo DZ, et al. Characteristics of hospitalizations for patients who use a structured clinical care program for children with medical complexity. *J Pediatr*. 2011;159(2): 284–290
9. Gold JM, Hall M, Shah SS, et al. Long length of hospital stay in children with medical complexity. *J Hosp Med*. 2016; 11(11):750–756
10. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttman A. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012; 130(6). Available at: www.pediatrics.org/cgi/content/full/130/6/e1463

11. Russell CJ, Simon TD. Care of children with medical complexity in the hospital setting. *Pediatr Ann.* 2014;43(7): e157–e162
12. Edwards JD, Houtrow AJ, Vasilevskis EE, et al. Chronic conditions among children admitted to U.S. pediatric intensive care units: their prevalence and impact on risk for mortality and prolonged length of stay*. *Crit Care Med.* 2012;40(7): 2196–2203
13. 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(1):108–113.e1
14. Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. Profile of medical charges for children by health status group and severity level in a Washington State Health Plan. *Health Serv Res.* 2004;39(1): 73–89
15. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood).* 2014;33(12):2199–2206
16. Berry JG, Agrawal RK, Cohen E, Kuo DK. *The Landscape of Medical Care for Children With Medical Complexity.* Alexandria, VA; Overland Park, KS: Children's Hospital Association; 2013
17. Glader L, Plews-Ogan J, Agrawal R. Children with medical complexity: creating a framework for care based on the International Classification of Functioning, Disability and Health. *Dev Med Child Neurol.* 2016;58(11):1116–1123
18. Simon TD, Mahant S, Cohen E. Pediatric hospital medicine and children with medical complexity: past, present, and future. *Curr Probl Pediatr Adolesc Health Care.* 2012;42(5):113–119
19. White CM, Thomson JE, Statile AM, et al. Development of a new care model for hospitalized children with medical complexity. *Hosp Pediatr.* 2017;7(7): 410–414
20. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med.* 2007;161(10):937–944
21. Cohen E, Friedman J, Nicholas DB, Adams S, Rosenbaum P. A home for medically complex children: the role of hospital programs. *J Healthc Qual.* 2008;30(3): 7–15
22. Adame N, Rocha ME, Loudon C, Agrawal R. Pediatric hospitalists' perspectives on the care of children with medical complexity. *Hosp Pediatr.* 2011;1(1): 30–37

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