Variable Identification of Children With Medical Complexity in United States PICUs

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OBJECTIVES: Children with medical complexity are at increased risk for critical illness and adverse outcomes. However, there is currently no consensus definition of medical complexity in pediatric critical care research.

DESIGN: Retrospective, cross-sectional cohort study.

SETTING: One hundred thirty-one U.S. PICUs participating in the Virtual Pediatric Systems Database.

SUBJECTS: Children less than 21 years old admitted from 2017 to 2019. Multisystem complexity was identified on the basis of two common definitions of medical complexity, Pediatric Complex Chronic Conditions (CCC), greater than or equal to 2 qualifying diagnoses, and Pediatric Medical Complexity Algorithm (PMCA), complex chronic disease.

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: Of 291,583 index PICU admissions, 226,430 (77.7%) met at least one definition of multisystem complexity, including 168,332 patients identified by CCC and 201,537 by PMCA. Of these, 143,439 (63.3%) were identified by both definitions. Cohen kappa was 0.39, indicating only fair agreement between definitions. Children identified by CCC were younger and were less frequently scheduled admissions and discharged home from the ICU than PMCA. The most common reason for admission was respiratory in both groups, although this represented a larger proportion of CCC patients. ICU and hospital length of stay were longer for patients identified by CCC. No difference in median severity of illness scoring was identified between definitions, but CCC patients had higher inhospital mortality. Readmission to the ICU in the subsequent year was seen in approximately one-fifth of patients in either group.

CONCLUSIONS: Commonly used definitions of medical complexity identified distinct populations of children with multisystem complexity in the PICU with only fair agreement.

KEY WORDS: chronic disease; epidemiology; intensive care unit; pediatric

Children with medical complexity (CMC) are at increased risk for critical illness and adverse outcomes. Two commonly used definitions of CMC are Complex Chronic Conditions (CCC) and the Pediatric Medical Complexity Algorithm (PMCA), both of which use diagnosis codes to identify organ system involvement (1–5). The number of CCC diagnoses an individual patient has is often used as a proxy for multisystem complexity in research (e.g., a patient with a tracheostomy and static encephalopathy is more "complex" than one with a tracheostomy alone), whereas PMCA includes explicit categories for the complexity of a patient's condition based on multisystem involvement (e.g., cystic fibrosis) or progressivity (e.g., neurodegenerative disorders). Prior research has established that CMC compose a majority of PICU admissions and bed-days, accounting

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for up to 75% of costs despite their low population prevalence, and that the number of CMC is expected to increase (6–8). There is no consensus definition of CMC in pediatric critical care or in the understanding of how populations of children identified by individual definitions vary. We aimed to identify the demographic and clinical differences and the degree of overlap between definitions of CMC among critically ill children.

MATERIALS AND METHODS

Database

We performed a multicenter cross-sectional study using Virtual Pediatric Systems Database (VPS, LLC), a prospectively-collected cohort of PICU admissions. Patients are assigned a unique identifier, which permits longitudinal monitoring at a single institution but cannot be followed across multiple institutions. We included data from 131 centers in the United States.

Patients

We included patients less than 21 years old with a PICU encounter between 2017 and 2019, retaining only the first encounter per patient during the study period.

Definitions

We classified patients using previously published diagnosis-based medical complexity criteria (**Supplemental Digital Content 1**, http://links.lww.com/PCC/C248). Diagnoses in VPS are coded using proprietary STAR codes, which we crosswalked to *International Classification of Diseases*, 10th revision (ICD-10) codes using a VPS-provided algorithm. All classifications of diagnoses in VPS were included. CCC assigns one of 10 mutually exclusive diagnosis categories to each code; each may also be associated with one or both categories of technology dependence or transplant (2, 9). PMCA assigns patients to one of three mutually exclusive categories: complex chronic disease, noncomplex chronic disease, or no chronic disease (5). We defined multisystem complexity as greater than or equal to 2 CCC diagnoses or PMCA complex chronic disease as each conceptually recognizes children with multisystem involvement.

Analysis

We assessed descriptive data for each complexity grouping and for all admissions. We did not perform tests of significance between definitions of multisystem complexity due to the overlapping patient populations. We constructed Euler diagrams and calculated Cohen kappa to assess the degree of overlap between groups, classifying a result of greater than or equal to 0.8 as almost perfect agreement, 0.61–0.79 as substantial, 0.41–0.60 as moderate, 0.21–0.40 as fair, and 0–0.20 as slight agreement (10). As post hoc analyses, we examined: 1) the overlap between definitions when comparing 1, 2, 3, or greater than or equal to 4 CCC diagnoses with PMCA complex chronic disease and 2) the characteristics of children identified by only the CCC or PMCA definition. Analyses were performed using the "eulerr" (Version 6.1.0) package (11) in R Version 4.1.2 (R Foundation for Statistical Computing, Vienna, Austria). This study was determined to be nonhuman subject research by the University of Minnesota and followed the Strengthening the Reporting of Observational Studies in Epidemiology reporting guidelines for cross-sectional studies (**Supplemental Digital Content 2**, http://links.lww.com/PCC/C248).

RESULTS

Differences Between Definitions of Medical Complexity

Of 291,583 index PICU admissions, 226,430 (77.7%) met at least one definition of multisystem complexity. Compared with children with CCC, children identified by PMCA were older (**Table 1**). Patients identified using PMCA were more commonly scheduled admissions and discharged home from the ICU. ICU and hospital lengths of stay were longer for patients identified by CCC. No difference in median severity of illness scoring using the Pediatric Risk of Mortality III was identified, but PMCA patients had lower inhospital mortality. Children identified by CCC only were younger, more commonly had respiratory illness, were more commonly admitted urgently, and required additional respiratory support compared with children identified by PMCA only. The children in the overlap group required higher levels of therapeutic support and had longer lengths of stay, mortality, and subsequent ICU utilization than those identified by only a single definition (**Supplemental Digital Content 3**, http://links.lww.com/PCC/C248). Additional procedural

TABLE 1.
Demographic and Clinical Characteristics of Patients Identified as Having Multisystem Complexity by Complex Chronic Condition or Pediatric Medical Complexity Algorithm

Characteristic (*n*[%])	Complex Chronic Condition (*n* = 168,332; 57.7% of total patients)	Pediatric Medical Complexity Algorithm (*n* = 201,537; 69.1% of total patients)
Patient characteristics		
Age category		
Neonate (birth to 28 d)	7,339 (4.4)	7,766 (3.9)
Infant (29 d to < 2 yr)	62,256 (37.0)	61,760 (30.6)
Preschool (2 to < 6 yr)	31,483 (18.7)	36,938 (18.3)
School age (6 to < 12 yr)	28,267 (16.8)	36,723 (18.2)
Adolescent (12 to < 21 yr)	38,987 (23.1)	58,350 (29.0)
Female sex	73,866 (43.9)	90,260 (44.8)
Primary diagnosis category		
Respiratory or ear, nose, and throat	68,050 (40.5)	59,470 (29.5)
Neurologic	24,423 (14.5)	31,652 (15.7)
Injury/poisoning	14,271 (8.5)	20,071 (10.0)
Cardiovascular	14,942 (8.9)	22,002 (10.9)
Infectious	12,367 (7.3)	12,459 (6.2)
Oncologic	6,880 (4.1)	10,412 (5.2)
Endocrine	3,454 (2.1)	10,076 (5.0)
Admission characteristics		
Scheduled admission (≥12 hr in advance)	33,258 (19.8)	54,720 (27.2)
Admitted from the emergency department	89,451 (53.1)	99,977 (49.6)
Admitted from procedural area[a]	38,640 (23.0)	60,869 (30.2)
Pediatric Risk of Mortality III score (median [IQR])	1.00 (0–5)	1.00 (0–5)
Baseline tracheostomy	6,769 (4.0)	6,786 (3.4)
Procedural exposure		
Continuous positive airway pressure	13,917 (8.3)	11,703 (5.8)
Bilevel positive pressure ventilation	19,974 (11.9)	17,851 (8.9)
Mechanical ventilation	56,910 (33.8)	56,971 (28.3)
Cardiopulmonary resuscitation	1,987 (1.2)	1,975 (1.0)
Extracorporeal membrane oxygenation	1,733 (1.0)	1,733 (0.9)
Renal replacement therapy	2,335 (1.4)	2,475 (1.2)
Arterial line	39,334 (23.4)	52,484 (26.0)
Percutaneous central line	28,684 (17.0)	32,508 (16.1)
Intracranial pressure monitoring	4,636 (2.8)	5,015 (2.5)
Outcomes		
ICU length of stay, d (median [IQR])	2.06 (1.06–4.71)	1.76 (0.951–3.89)
Hospital length of stay, d (median [IQR])	4.91 (2.59–10.9)	4.32 (2.21–9.76)
Mortality	5,397 (3.2)	5,339 (2.6)
Discharge to general ward	109,211 (64.9)	12,6,431 (62.7)
Discharge to home	28,623 (17.0)	40,197 (19.9)
Patients with ICU readmissions in the year following discharge	33,146 (19.7)	37,950 (18.8)

IQR = interquartile range.

[a]Procedural areas defined as the operating room, catheterization/procedure suite, or postanesthesia care unit.

Patients could be identified by one or both definitions.

exposure and outcome data divided by patients identified by only one of the definitions or both definitions are available in Supplemental Digital Content 3 (http://links.lww.com/PCC/C248).

Overlap Between Definitions of Multisystem Complexity

The CCC definition identified 168,332 (57.7%) patients and PMCA 201,537 (69.1%) patients. The overlap of the definitions comprised 143,439 (49.2%) patients (**Supplemental Digital Content 4*B***, http://links.lww.com/PCC/C248). Cohen kappa was 0.39, indicating only fair agreement between definitions (10). Patients in both groups were most commonly admitted from the emergency department and procedural areas. The most common reason for admission was respiratory in both groups. Readmission to the ICU in the subsequent year occurred in approximately one-fifth of patients in both groups. When evaluating differing overlap between CCC criteria and PMCA, κ ranged from 0.19 to 0.49 (**Supplemental Digital Content 4*A, C***, and ***D***, http://links.lww.com/PCC/C248). The greatest agreement between definitions was with a single CCC diagnosis.

Comparisons to Other Cohorts

We compared our cohorts of patients to select other studies of CMC using variations on the CCC and PMCA definitions (**Table 2**). Demographic and clinical characteristics for subgroups of children with different levels of medical complexity are found in **Supplemental Digital Content 5** (http://links.lww.com/PCC/C248) (PMCA) and **Supplemental Digital Content 6** (http://links.lww.com/PCC/C248) (CCC).

DISCUSSION

CMC are a dominant population in the pediatric ICU (6–8). We used a retrospective, multicenter cross-sectional cohort of children to identify the extent of overlap among children identified by two definitions of pediatric CMC. Although some overlap was identified, distinct patient cohorts were identified with only fair agreement, thereby highlighting important clinical, demographic, and outcome differences between the groups.

The highest κ for agreement was between PMCA complex chronic disease and patients with at least one CCC diagnosis, suggesting that the PMCA definition includes patients with current single organ disease, potentially through inclusion of progressive diseases and malignancies. Notably, PMCA considers mental health and psychiatric diagnoses as one of its potential areas of complexity; these are not included in the CCC definitions. With the prevalence of CMC increasing, we will need initiatives across a range of areas to better serve this heterogeneous population. Given that these definitions were initially developed for different purposes, progress requires a common understanding and definition of medical complexity across studies. The identified differences in children identified by only one of the definitions (or by both definitions) highlight the importance of appropriate cohort selection for risk adjustment or for study inclusion so that consistency in study interpretation can be ensured.

We identified a similar proportion of children meeting at least one definition of medical complexity to other studies of critically ill patients (6–8). These proportions are higher compared with other work evaluating all hospitalized children (12). Mortality in our cohort was approximately half of that in a prior multicenter study of tertiary-care PICUs (6). Patients in that study were younger, were more frequently admitted for circulatory diagnoses, and more frequently required invasive procedures. Compared with another study using a modified CCC definition in the VPS dataset (7), we found a similar distribution of diagnosis reasons, nonelective admissions, illness severity, length of stay, and mortality rate. Procedural exposure was not assessed in that study. The etiology of the differences between these study cohorts may represent variations in study design (including choice of definition, as in this study), patient epidemiology, and clinical practice, or a combination of the three.

Our findings are subject to limitations, including the use of STAR codes instead of ICD-10 codes in VPS, requiring an additional crosswalk procedure prior to classification. These limitations apply to any

TABLE 2.
Comparison of Selected Features of "Children With Medical Complexity" Across Definitions and Datasets

Characteristic	Heneghan CCC	Edwards CCC[a]	Heneghan PMCA	Chan PMCA[b]
Inclusion criteria	Index encounters for patients < 21 yr old, ≥ 2 CCC categories assessed by CCC 2.0[c]	All encounters for patients < 21 yr old, classified by expert review of VPS diagnoses resulting from a modified version of CCC 1.0[d]	Index encounters for patients < 21 yr old, complex chronic disease as assessed by PMCA 3.0[e]	All encounters for children <19 yr old, complex chronic disease as assessed by PMCA 1.0[f]
Study year	2017–2019	2008	2017–2019	2012–2013
Database	VPS	VPS	VPS	Pediatric Health Information Systems
Proportion of ICU Admissions	57.7%	52.8%	69.1%	53.0%
Age	37.0% infant (29 d to 2 yr), 23.1% adolescent (12–21 yr)	Median 59 mo (IQR, 12–152)	30.6% infant (29 d to 2 yr), 29.0% adolescent (12–21 yr)	27.6% toddler (1–5 yr), 25.5% adolescent (11–18 yr)
Mortality rate	3.2%	3.9%	2.6%	5.7%
Primary diagnosis	Respiratory/ENT (40.5%), neurologic (14.5%), and injury/poisoning (8.5%)	Respiratory (27.3%), neurologic (21.7%), and procedure (15.6%)	Respiratory/ENT (29.5%), neurologic (15.7%), and injury/poisoning (10.0%)	Respiratory (18.8%), circulatory (18.6%), and nervous system (18.5%)
Postprocedural	23.0%	47.5% (pre-/postoperative)	30.2%	41.3% (planned procedure)
ICU length of stay, d (IQR)	2.06 (1.06–4.71)	1.9 (1–4.8)	1.76 (0.95–3.89)	3 (1–7)
ICU procedural exposure	33.8% mechanical ventilation and 17.0% percutaneous central line	Not described	28.3% mechanical ventilation and 16.1% percutaneous central line	44.9% mechanical ventilation and 29.8% central line

CCC = complex chronic conditions, ENT = ear, nose, and throat, IQR = interquartile range, PMCA = Pediatric Medical Complexity Algorithm, VPS = Virtual Pediatric Systems Database.

[a]Edwards et al (7).

[b]Chan et al (6).

[c]Feudtner et al (2).

[d]Feudtner et al (1).

[e]Simon et al (5).

[f]Simon et al (3).

The CCC and PMCA definitions have been updated over time to accommodate the transition to *International Classification of Diseases,* 10th Edition codes and to add additional groups (e.g., "technology dependence") to improve performance of the classification systems.

attempt to operationalize these standardized definitions of medical complexity in this dataset. Another concern with the use of administrative data is that it may inadequately capture more nuanced challenges in the identification of CMC, such as whether qualifying diagnoses are long-standing or the initial presentation of a chronic condition. However, these definitions are commonly applied in the literature and, thereby, constitute an essential component in the current understanding of medical complexity. In order to establish appropriate baseline data, relevant clinical conditions, and an understanding of utilization and outcomes, it is

necessary to have an agreed-upon definition and analytical approach that permits comparison across institutions and time periods.

CONCLUSIONS

This analysis of a large, multicenter database of pediatric ICU admissions identified cohorts of children with some overlap but key clinical, demographic, and outcome differences. Although many characteristics were shared across groups, investigators and clinicians should be mindful of their differences. Additionally, limitations in adapting these common definitions of medical complexity to research datasets make research on this important patient population more challenging. Our data demonstrate the differences between two of the most common definitions and support the imperative to develop a consensus definition, which can be applied both at the bedside and administratively in order to inform future studies.

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REFERENCES

1. Feudtner C, Christakis DA, Connell FA: Pediatric deaths attributable to complex chronic conditions: A population-based study of Washington State, 1980-1997. *Pediatrics* 2000; 106:205–209
2. Feudtner C, Feinstein JA, Zhong W, et al: Pediatric complex chronic conditions classification system version 2: Updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatr* 2014; 14:199
3. Simon TD, Cawthon ML, Stanford S, et al: Pediatric medical complexity algorithm: A new method to stratify children by medical complexity. *Pediatrics* 2014; 133:e1647–e1654
4. Simon TD, Cawthon ML, Popalisky J, et al: Center of excellence on quality of care measures for children with complex needs (COE4CCN). Development and validation of the Pediatric Medical Complexity Algorithm (PMCA) Version 2.0. *Hosp Pediatr* 2017; 7:373–377
5. Simon TD, Haaland W, Hawley K, et al: Development and validation of the Pediatric Medical Complexity Algorithm (PMCA) version 3.0. *Acad Pediatr* 2018; 18:577–580
6. 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
7. 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; 40:2196–2203
8. Odetola FO, Gebremariam A, Davis MM: Comorbid illnesses among critically ill hospitalized children: Impact on hospital resource use and mortality, 1997-2006. *Pediatr Crit Care Med* 2010; 11:457–463
9. Feinstein JA, Russell S, DeWitt PE, et al: R Package for Pediatric Complex Chronic Condition Classification. *JAMA Pediatr* 2018; 172:596–598
10. Landis JR, Koch GG: The measurement of observer agreement for categorical data. *Biometrics* 1977; 33:159–174
11. Larsson J. eulrr: Area-Proportional Euler and Venn Diagrams With Ellipses. R package version 6.1.0. 2020. Available at: https://cran.r-project.org/web/packages/eulerr/. Accessed February 17, 2022
12. Heneghan JA, Goodman DM, Ramgopal S: Demographic and clinical differences between applied definitions of medical complexity. *Hosp Pediatr* 2022; 12:654–663