Pediatric Complex Chronic Condition System
Lisa C. Lindley, PhD, RN

The pediatric complex chronic condition (CCC) system is the gold standard in classifying patients younger than 18 years who are seriously ill in pediatric research. It originated in 2000 as a research tool to categorize CCCs defined as medical conditions that would reasonably be expected to last at least 12 months and involve either several organ systems or 1 organ system requiring specialty pediatric care. For over 2 decades, the system has been used extensively to identify samples and create measures of health, illness severity, and multimorbidity. The first CCC version (V1) was created using 1980 to 1997 Washington State death certificate data from youths younger than 1 year to 18 years of age. V1 had 9 diagnostic categories (ie, neuromuscular, cardiovascular, respiratory, renal, gastrointestinal, hematological or immunological, metabolic, other congenital or genetic defect, and malignant condition) that corresponded to specific CCC International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes. This version was evaluated in a national sample using 1979 to 1997 US death certificates (individuals aged <1 year to 24 years). V2 was released in 2014, and it included significant revisions: conversion to International Statistical Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) codes; ICD code updates; procedure code additions; and 3 new diagnostic categories (ie, premature or neonate, technology dependence, and transplant). V2 was evaluated with US mortality data and national inpatient data (eg, the Healthcare Cost and Utilization Project Kids’ Inpatient Database and the Healthcare Cost and Utilization Project Nationwide Emergency Department Sample) and has undergone psychometric testing in an infant population.

Feinstein et al report on the development and comparison of the most recent revision (V3) of the CCC system. V3 updates include modifications to new, missing, and retired ICD-10-CM and procedure codes. The authors used a General Equivalence Mappings electronic tool and manual mapping to review over 6900 codes. The authors then compared the performance of V3 with V2 by leveraging national data from the 2009 to 2019 Pediatric Health Information Systems and the 2009 to 2019 Medicaid Merative MarketScan Research Databases among hospitalized patients aged 0 to 18 years. Comparison between V3 and V2 was assessed by regressing patient outcomes (ie, hospital length of stay and in-hospital mortality) on the presence of a CCC as the only covariate with R² and Akaike information criterion measures of fit. The authors report that V3 was comparable with V2. In the Pediatric Health Information Systems data, V3 identified 38.3% of patients younger than 18 years as having any CCC vs 40.1% in V2. Nonsignificant differences were also found within the diagnostic CCC categories, along with inpatient length of stay and in-hospital mortality. Similar patterns were found using the Medicaid data. No psychometric testing was conducted.

The authors recommend using the newest V3 of the CCC system for research because it incorporates the evolving ICD-10 system. The article reflects the practical and ongoing housekeeping associated with research measures. ICD-10 codes are continually being added, deleted, and modified, and the CCC system, which is based on the ICD and procedure codes, needs to keep pace. Feinstein et al are to be commended for their significant effort to update codes, especially ahead of the imminent US transition to the International Classification of Diseases, 11th Revision (ICD-11). V3 is a critical step in assuring that the CCC system is prepared to migrate to the ICD-11.

For pediatric researchers, V3 offers an interesting shift in the evaluation of the CCC system from mortality to inpatient-only data. V1 and V2 included mortality data in the evaluation, and those early versions of the CCC were commonly used in pediatric hospice and palliative care research to identify patients younger than 18 years who would most likely die with a serious illness. However, given the
advances in pediatric medicine and the extended lifespan of seriously ill US pediatric patients, evaluating the CCCs with inpatient data is more aligned with the current population of seriously ill pediatric patients than evaluating them with death data. Pediatric patients with CCCs will continue to frequent the inpatient setting because of the complexity of their CCCs, but they are increasingly living longer and transitioning from pediatric to adult health care. As an interesting side note, the authors suggested that the CCC system might perform differently in other settings of care (e.g., outpatient or emergency care), which suggests opportunities to test the robustness of the CCC system measure.

Conversely, Feinstein et al. did not provide the level of analytic support for pediatric researchers as in prior versions. In V3, the authors included extensive supplemental content with a list of revised V3 CCC categories and diagnostic and procedure codes, a complete list of V3 codes, and additional tables of findings. The complete list of V3 codes, for example, is helpful for developing programming coding for implementing the CCC system using statistical packages; however, it is still a labor-intensive process to write the programming language for a new list of diagnostic and procedure codes. In prior versions, the authors had provided SAS and Stata programming language in the supplements, which was useful. Given the depth and breadth of code changes in V3, including programming language might have eased the transition for researchers shifting to V3.

A key message from the study is the importance of updating pediatric measures and validating their use for research. Although additional measurement assessment in other pediatric settings (e.g., community and home-based) with rigorous psychometric testing (e.g., agreement, discrimination, calibration, and accuracy) is warranted, pediatric researchers should have confidence based on the study’s findings that V3 will perform as well as V2 in identifying pediatric patients with CCCs in research data and operationalizing CCC as a study measure.

ARTICLE INFORMATION
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Corresponding Author: Lisa C. Lindley, PhD, RN, College of Nursing, University of Tennessee, Knoxville, Nursing Education Building, 1412 Circle Dr, Knoxville, TN 37996 (llindley@utk.edu).
Author Affiliation: College of Nursing, University of Tennessee, Knoxville.
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REFERENCES