The correct identification of children with chronic conditions and/or medical complexity in administrative data is important for assessing hospital quality, accurately comparing severity of illness across hospitals, and examining individual outcomes for patients with chronic conditions. As such, many researchers have embarked on the challenging quest to accurately identify these patients in administrative data. In this issue of Hospital Pediatrics, Berry et al and Simon et al present different approaches to such identification, each advancing the field by enhancing researchers’ abilities to accurately identify and classify children with chronic conditions.

Although individual chronic conditions may be relatively easily identified from administrative data, using such data to further classify patients according to complexity is particularly challenging. Clinically apparent severity is not always clear through individual billing codes. For example, epilepsy may cause significant issues with frequent seizures impacting the overall quality of life, or may indicate that the epilepsy was well-controlled and a few seizures occurred years ago. Yet in these different clinical scenarios, the administrative billing data may be identical. Additionally, many researchers use administrative data to describe health utilization among patients with chronic conditions and medical complexity. In these instances, there is an inherent circularity. For example, some methods to identify complex conditions, including the Agency for Healthcare and Research Quality’s Clinical Classification Software (CCS) codes and Chronic Condition Indicator (CCI), rely on a single hospital encounter to identify complexity and allow researchers to categorize patients by the number of chronic diagnoses they have been assigned. The longer a child remains hospitalized, the more diagnoses they accrue, the more complex they appear by this coding system, and the higher their health care utilization, hence a circular pattern appears.

A similar paradox exists for algorithms using multiple encounters to identify complexity, including the Pediatric Medical Complexity Algorithm (PMCA). Berry et al have updated and adapted the Agency for Healthcare and Research Quality’s CCS and CCI coding software to make it pediatric-specific, as previous pediatric papers using this chronic care indicator have relied on the adult derived algorithm. This upgrade significantly advances the ability to correctly identify children with chronic conditions from cross-sectional, administrative data. The CCS and CCI adaptation accounts for diagnoses that may be chronic in adults but are typically acute in children (eg, cystitis, lymphadenitis), as well as designating some conditions previously categorized as nonchronic as chronic (eg, obesity, chronic kidney disease). The authors also created new organ system categories and then reassigned diagnoses to these new...
categories. The authors define children with multiple chronic conditions as those who have “2 or more chronic conditions that affect different organ systems.” The primary findings presented are from the Kids’ Inpatient Database and, thus, are representative of hospitalizations for pediatric hospitalizations nationally (including those at children’s hospitals and adult hospitals who serve children). In sum, 36.5% of hospitalizations occurred in children with 1 chronic condition (as identified by the CCS and CCI software) and 29.3% in children with at least 2 chronic conditions; furthermore, mental health conditions were a particularly significant contributor to hospital days. These rates represent a stark difference from 10.1% of pediatric hospitalizations nationally with at least 1 complex chronic condition in 2006.13,14 Although certainly some of the difference in rates of hospitalization can be attributed to differences in classifying conditions (CCS and CCI versus complex chronic condition), there is a growing body of literature to suggest a rise in chronic conditions, as well as medical complexity within children’s hospitals.15 Additionally, although children with multiple chronic conditions are often more complex than those with a single chronic condition, this is not always true (e.g., a child with asthma and eczema) and, thus, the CCS and CCI strength is identifying chronic conditions, which may or may not confer complexity. A significant weakness in the CCS and CCI adaptation for pediatrics is that although the new categorizations were developed by knowledgeable clinicians and have face validity, they have not been formally validated by medical record review.

In contrast, the PMCA version 2.0 presented by Simon et al1 has undergone rigorous validation with medical record review. The original PMCA algorithm lacked sensitivity in identifying the noncomplex chronic group of children (45% in Medicaid claims data).4 In this edition of Hospital Pediatrics, the original version of PMCA (1.0) was updated through review of 300 randomly selected medical records at Seattle Children’s Hospital, noting discrepancies between the algorithm and the medical record review. These discrepancies were used to develop PMCA 2.0. Version 2.0 was then retested in the same cohort of 300 patients with some improvement in sensitivity for the noncomplex chronic population (60%). Notably, the algorithm performs optimally with 2 to 3 years of claims data, which allows enough time to accrue accurate billing diagnoses. By using the longer window of claims data, the PMCA version 2.0 performs nearly flawlessly at identifying children without chronic disease (with 100% sensitivity and 97% specificity). Overall, version 2.0 appears to be an improvement over version 1.0. However, like version 1.0, the algorithm relies on longitudinal data, making its application to cross-sectional data sets, such as the Kids’ Inpatient Database, less accurate, although it has been done.9 Additionally, PMCA has been developed and validated in a tertiary care children’s hospital, which leaves some uncertainty on how well the algorithm would perform at other institutions. Finally, the PMCA version 2.0 was reassessed in the same cohort of children used to refine the algorithm. This technique, although certainly the most efficient, does mean that the PMCA version 2.0 may be overfitted to the population of 300 kids. In other words, there may be minor idiosyncrasies with the 300 children included in the study, which shaped the development of the 2.0 algorithm, and may not apply to patients outside the study. Nevertheless, despite the real-world limitations of validating the PMCA, the existence of a validated, readily available method to distinguish children with complex chronic disease, noncomplex chronic disease, and children without chronic disease is incredibly valuable.

Correctly identifying children with chronic conditions and medical complexity in administrative data sets remains challenging yet crucial for clinicians, researchers, and policy makers. Both the pediatric-adapted CCS and CCI codes and the PMCA version 2.0 will enhance clarity moving forward. As a result, researchers and policy makers now have 2 new and improved tools to sift through the administrative data sandbox and correctly identify children with chronic conditions.

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