

The High Value of Blurry Data in Improving Pediatric Emergency Care

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Pediatric emergency care research suffers from a generalizability problem. Such research in the United States largely relies on data collected from within academic medical centers or large health systems with the infrastructure to conduct and publish clinical research. Such research also includes studies ranging from trials of fluid infusion rates for diabetic ketoacidosis¹ from the Pediatric Emergency Care Applied Research Network to retrospective cohort studies defining the incidence of herpes simplex virus by week of life.² This research is extremely valuable because it informs how to distribute limited health care resources and where to focus efforts to improve care. However, academic and large health systems are a narrow lens through which to view care because 90% of children do not visit academic pediatric emergency departments (EDs) but rather visit community general EDs.³ Children who visit academic EDs differ from the larger population of children demographically, especially related to their access to, need for, and receipt of acute care. Because of these differences, epidemiological insights cannot always be generalized beyond the populations that academic centers serve. Large, population-based, administrative databases offer 1 solution to this problem. Administrative data are collected in the course of routine clinical operations and include claims, which are billing records. These databases do not typically contain clinical information and instead contain demographics, diagnoses, procedures, and billing information, such as charges. They therefore represent a blurrier but wider field of view than the narrow lens of academia-based investigation, thereby allowing more complete insight into diseases and outcomes. Furthermore, these databases eliminate the selection bias introduced by studying only children who present to academic hospitals, which often outweighs the advantages of prospective data collection.

The main advantages of administrative data are scale, availability, completeness, and representativeness. First, administrative data sources can include millions of unique patients and encounters with care. This allows for identification of rare conditions (such as myocarditis) or measurement of uncommon but key outcomes (such as pediatric mortality) with high precision. It also overcomes the inherent bias of case control studies that are often employed to investigate rare outcomes. Second, administrative data are frequently more easily obtained because no new collection effort is needed. Third, these data offer a more complete picture of illness and care, allowing patients to be managed between institutions, care systems, and geographic regions. This reduces loss to follow-up, exposes patterns of health care use, and illuminates differences in access. Additionally, because rural and nonacademic health systems have been slow to adopt electronic health records, administrative data are the only efficient means to identify, recruit, and manage these patients.⁴ Finally, administrative data are frequently more representative than traditional data sources that rely on recruiting research participants at academic centers. This is critically important because children in nonurban areas without research infrastructure go silently unmeasured.

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We believe it is the representativeness and generalizability of administrative data sources that, when properly measured, often outweighs the absence of direct measurement of clinical phenomena.

These 4 advantages are present to varying degrees depending on the data source. The Agency for Healthcare Research and Quality Healthcare Cost and Utilization Project publishes the Kids' Inpatient Database and Nationwide Emergency Department Sample, which both have high representativeness as national samples at the expense of a breadth of data elements. All-payer claims databases and large insurer databases, such as Medicaid, Optum, and Aetna databases, share similar characteristics. By contrast, the Pediatric Health Information System (PHIS) is relatively unrepresentative, because it is drawn only from freestanding pediatric hospitals. Notwithstanding this disadvantage, even the PHIS contains substantial geographic breadth, if not urban-rural representativeness.

To highlight certain ways in which data acquired through research at academic centers are nonrepresentative, we used the Nationwide Emergency Department Sample from 2016 to demonstrate differences in characteristics of ED visits to hospitals classified as metropolitan teaching, metropolitan nonteaching, or nonmetropolitan (in which there are few teaching hospitals).⁵ Visit counts were survey weighted to generate national estimates. Children <18 years old visiting academic EDs are more likely to be young, privately insured, and urban residing (Fig 1). They are more likely to live in a lower-income area compared with visitors of metropolitan nonteaching hospitals but less likely than visitors to nonmetropolitan hospitals. Thus, studying pediatric emergency care in academic institutions leads to an inherently biased sample.

Unfortunately, large databases, especially those with mostly administrative data, are sometimes considered inferior to directly observed clinical care because they measure epiphenomena: what was coded or billed instead of direct clinical documentation or detailed medical record data. Because of this perception, studies

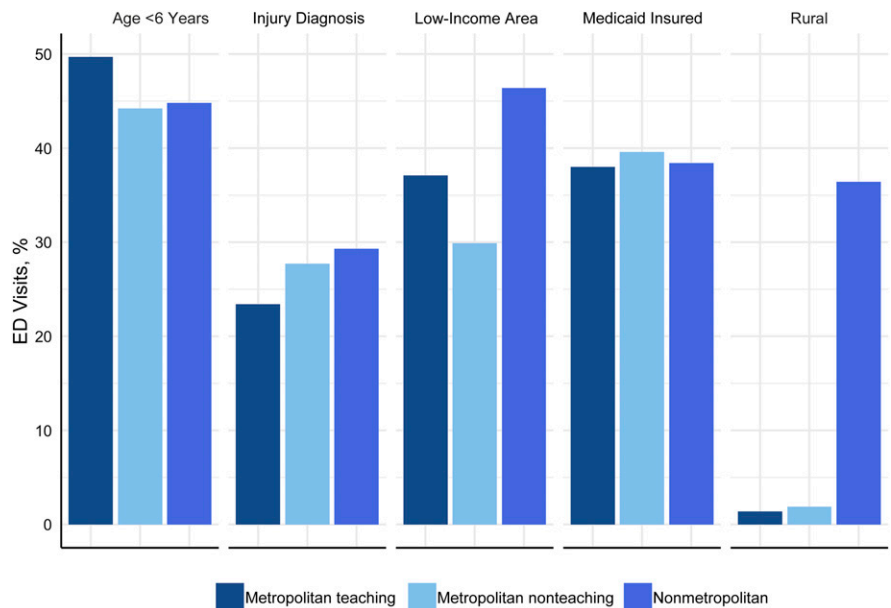


FIGURE 1 Differences in demographic characteristics depending on the teaching status of the ED.

relying on administrative data rarely lead to rapid adoption of clinical innovations at the bedside. As an example, a study of children with osteomyelitis used administrative data to demonstrate that early oral antimicrobial therapy was superior to prolonged intravenous therapy for serious safety outcomes without an increase in treatment failure.⁶ However, 6 years passed before a more traditional, confirmatory cohort study demonstrated the same conclusion and led to practice change.⁷ We believe quality-improvement methodology provides a means to carefully making early practice change, testing the effects of changes, and making rapid cycle improvements while monitoring for unanticipated harms.

Administrative data cannot answer every question and are most directly suited to understanding disease epidemiology and discerning how clinicians practice. For instance, insurance claims can reveal both the changing incidence of appendicitis and whether ultrasonography is cost-effective in its assessment.⁸ Claims can reveal whether patients have surgical complications even if subsequent care occurred in different facilities. These data can demonstrate whether pain management disparities exist or appendiceal perforation rates differ by geography, creating a basis for targeted

intervention.⁹ And used creatively, large data sets could show whether specific childhood illnesses are associated with subsequent appendicitis, suggesting a mechanistic link. Therefore, administrative data studies may best be viewed as complementary rather than inferior to traditional studies. Experimental studies, careful observational cohorts, and even chart reviews all have a crucial place in the development of medical knowledge and cannot be replaced by study of databases. As administrative data sources include more clinical information, the line between traditional studies and administrative data studies will become blurrier. Databases such as PHIS+, the Pediatric Emergency Care Applied Research Network Data Registry, and PEDSnet are examples of such hybrid databases. Research using these data sources may more easily answer the questions that face clinicians at the bedside, leading to practice improvement.

Large administrative data sets have limitations. Undercoding, upcoding, miscoding, misclassification, and missing data all create noise that is difficult to detect or correct. Two issues that deserve careful consideration are missing data and coding accuracy. Missing data issues threaten the validity of all studies. A large

burden of missing data on key exposure or outcome variables should prompt consideration of whether the findings of a study would be interpretable at all. When missing data are present, demographic comparisons between records with and without missing data should be conducted to make a case for whether confounding is likely to be present. Coding inaccuracy introduces bias. Frequently, preliminary study of the sensitivity and specificity of diagnosis codes for clinical diagnoses or outcomes is needed to establish the validity of using codes. Although these biases are of particular concern in research involving administrative data, bias is also introduced through the enrollment of subjects from few or homogeneous sites. Thus, a more complete picture of a problem can be developed by taking multiple research approaches, with concordance in findings indicating a greater likelihood of achieving truth.

The means to answer nuanced research questions exist today. Alongside the foundational experiments and cohort studies that make up the bedrock of pediatric research, administrative data are a capable tool: a blurry lens through which to view child health but a lens with a wide field of view. A truly universal, interoperable electronic health record would supplant administrative data for research but will not be available in the near future.¹⁰ Until then,

as administrative data sources improve and incorporate data collected at the bedside from the course of clinical care, the clarity of the view will improve. We have reached a point at which administrative data and the tools to analyze them deserve consideration as key sources in understanding the pediatric emergency care system.

REFERENCES

1. Kuppermann N, Ghetti S, Schunk JE, et al; PECARN DKA FLUID Study Group. Clinical trial of fluid infusion rates for pediatric diabetic ketoacidosis. *N Engl J Med*. 2018;378(24):2275–2287
2. Cruz AT, Freedman SB, Kulik DM, et al; HSV Study Group of the Pediatric Emergency Medicine Collaborative Research Committee. Herpes simplex virus infection in infants undergoing meningitis evaluation. *Pediatrics*. 2018; 141(2):e20171688
3. Hudgins JD, Monuteaux MC, Bourgeois FT, et al. Complexity and severity of pediatric patients treated at United States emergency departments. *J Pediatr*. 2017;186:145–149.e1
4. Heisey-Grove DM. Variation in rural health information technology adoption and use. *Health Aff (Millwood)*. 2016; 35(2):365–370
5. Healthcare Cost and Utilization Project (HCUP). Overview of the Nationwide

Emergency Department Sample (NEDS). 2019. Available at: <https://www.hcup-us.ahrq.gov/nedsoverview.jsp>. Accessed March 26, 2019

6. Zaoutis T, Localio AR, Leckerman K, Saddlemire S, Bertoch D, Keren R. Prolonged intravenous therapy versus early transition to oral antimicrobial therapy for acute osteomyelitis in children. *Pediatrics*. 2009;123(2):636–642
7. Keren R, Shah SS, Srivastava R, et al; Pediatric Research in Inpatient Settings Network. Comparative effectiveness of intravenous vs oral antibiotics for postdischarge treatment of acute osteomyelitis in children. *JAMA Pediatr*. 2015;169(2):120–128
8. Otero HJ, Crowder L. Imaging utilization for the diagnosis of appendicitis in stand-alone children's hospitals in the United States: trends and costs. *J Am Coll Radiol*. 2017;14(5):603–608
9. Goyal MK, Kuppermann N, Cleary SD, Teach SJ, Chamberlain JM. Racial disparities in pain management of children with appendicitis in emergency departments. *JAMA Pediatr*. 2015; 169(11):996–1002
10. Hebert PL, Katon JG. Repurposing of administrative data for research: still useful but for how much longer? *Pediatrics*. 2019;143(2):e20183293

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