Perfect is the enemy of good: Use of administrative databases in characterizing rare events and outcomes

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Central Message

Administrative database research is imperfect but necessary to study rare occurrences. The Pediatric Health Information System is used to explore the socioeconomic factors, and variation of ECMO after pediatric cardiac surgery.

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Racial disparities in rates of morbidity and mortality after pediatric cardiac surgery are well described,¹⁻⁵ yet the causes for these disparities remain unclear. Furthermore, although extracorporeal membrane oxygenation (ECMO) may be used to rescue critically ill children after cardiac surgery who would have otherwise not survived, there also exists significant practice variation with regard to ECMO use between providers and centers.⁶ In this retrospective database analysis using the Pediatric Health Information System database, Chan and colleagues⁷ thoughtfully explore the potential impact of race/ethnicity on variability in ECMO use and survival.

More than 130,000 pediatric patients undergoing cardiac surgery were identified in this Pediatric Health Information System cohort, spanning from 2004 to 2015; ECMO use in the entire cohort was 2.7%, or 3452 patients. Black race, other race, and government insurance were independent risk factors for mortality after congenital heart surgery (in line with previously published studies). In addition, these children had an increased risk of death without receiving ECMO support, whereas children of other race or with government insurance remained at higher odds of death after ECMO. In contrast to previous studies that demonstrated increased mortality of nonwhite⁷⁻⁹ or black patients^{10,11} on ECMO, black patients on ECMO support in this study were not found to have increased mortality. Finally, Hispanic children demonstrated decreased ECMO mortality in this study, which is similar to studies of Hispanic adults on ECMO (the “Hispanic paradox” of increased survival),^{12,13} but in contrast to the increased mortality previously reported for Hispanic children on ECMO.¹⁰ Although the reasons behind the racial disparity in survival after pediatric cardiac surgery remain unclear, variations in ECMO use emerged in this study as a possible element contributing to these disparities (among black children, children of other race, and children with government insurance).

Notably, the many inherent limitations of retrospective, administrative database research are well documented in the literature,¹⁴⁻¹⁸ and the authors of this study provide thorough attention to highlighting and mitigating the limitations of this study. However, until we have the means to access and analyze all data necessary to confidently answer our clinical questions, we will inevitably depend on data sources that are not designed or intended for hypothesis-driven inquiry. Recent work in linking different administrative databases^{19,20} seems promising to overcome some of these barriers, and many are optimistic about the potential for big data and analytics to transform clinical research.^{21,22} Nonetheless, in the absence of any “perfect” dataset to comprehensively characterize our ECMO questions, the authors have done a nice job with this study in inching toward the truth.

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