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Big Data for Small People- How Novel Data Collection Can Improve Pediatric Transplant Outcomes

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Kanneganti et al merged UNOS and PHIS data to perform the first assessment of center-level variation in acute rejection and biliary tract complications in the first year following pediatric liver transplantation (1). By combining these data sources, these authors have (1) created a novel, robust dataset for longitudinal study of pediatric liver transplant recipients and (2) have identified potentially new opportunities for quality improvement in post-pediatric liver transplantation morbidity. In their analysis, Kanneganti et al found significant center-level variation in acute rejection and, to a lesser degree, in biliary complications in the year following pediatric liver transplantation. These data would suggest that center-specific patient management post-transplant is a critical driver of pediatric liver transplant success. At first glance, these finding are expected, and in and of themselves, unlikely to foment great change. While identification of high performing centers in these arenas is a crucial first step to QI efforts, the true innovation here is the novel dataset created that can provide large, multicenter, and potentially longitudinal data on pediatric liver transplant recipients. By merging UNOS data with administrative data from PHIS, these data could also be leveraged to examine and compare costs in the future. This innovative methodology should serve as a platform for further investigation that could foster actionable quality improvement in pediatric transplantation.

Pediatric transplant surgery struggles with performance improvement. Robust statistical analysis, upon which impactful quality interventions spurn, is difficult because of clinical complexity, smaller center volumes, and relatively few clinical events. To generate improvement, both reliable data and a community for sharing best practices are needed. For example, initiatives like the Studies of Pediatric Liver Transplantation (SPLIT) Registry have robust data and an engaged community(2). However, the SPLIT registry requires centers to collect data, which is expensive, labor-intensive, and short-term in scope. The pediatric transplant cohort requires complex critical care, multiple hospitalizations, ongoing long-term care needs, and more. Capturing the data from these interactions via manual retrospective chart review is a herculean task. Kanneganti et al have overcome this obstacle by unifying two
large datasets. We now have “big data” across the population that is longitudinal. This is the most important advance from this work.

The authors were able to adjust for donor and recipient-level data from the merged dataset to more reliably identify center-level effects on meaningful but understudied outcomes of acute rejection and biliary complications. Using this study and its novel data, the pediatric transplant community can dig deeper into questions about how to improve care. If we are serious about improving care, we will have to transition from a purely research mindset to one of quality improvement. Precedent for transitioning to quality improvement already exists in pediatric transplant (2). Beyond this, there are many examples of how a community of clinicians committed to clinical improvement and humble inquiry can drive positive change. First, acquisition of high-quality data is critical to the success of quality improvement; the authors have bridged this gap nicely with their novel dataset. Equally as paramount is creating a non-competitive atmosphere that assembles expert physicians who can create a joint quality improvement plan that all participants will get behind (2-5). The first step to embracing these principles is de-identifying centers in order to eliminate judgment surrounding labels of "high performing" or "low performing." Centers may be aware they are low performing, which alone may motivate engagement; however, public labeling will prevent universal buy-in and is an ineffective QI method. (3). Sharing and discussing care pathways and protocols used at high performing centers is an effective improvement method for all centers. Care processes around clinical care, surgical technique, social care, and programmatic culture are all tangible domains for this work.

This study used innovative methods to merge two large datasets in order to perform a uniquely robust analysis and identify high performing centers in acute rejection and biliary complications following pediatric liver transplantation. Interestingly, no one center was universally a high or low performer, further underlining the fact that judgement-free collaboration amongst all pediatric transplant centers is essential for performance improvement. Transforming these findings into tangible gains for children's health requires creating an inclusive community. The
charge is on the transplant community to create a collaborative that identifies high-performing centers willing to share their care pathways. Achieving this requires analyses like this one to reliably identify high performers of clinically meaningful targets and then engaging diverse clinical care teams in collaborative quality improvement to better the health of children who receive transplants. Precedents from other fields demonstrate that with diverse and engaged collaboration across centers, performance improvement is possible.
References: