Bridging the gap between administrative data and clinical observations

TO THE EDITOR: We read with interest the administrative database study by Shweikeh et al.¹ (Shweikeh F, Al-Khouja L, Nuño M, et al: Disparities in clinical and economic outcomes in children and adolescents following surgery for tethered cord syndrome in the United States. J Neurosurg Pediatr 15:427–433, April 2015). The authors used the Kids’ Inpatient Database (KID) to look at hospital discharge data for pediatric patients who had undergone tethered cord release (TCR) surgeries. Patient demographics, characteristics, complications, and utilization associated with these hospitalizations are described. The authors concluded that operative management has increased over time, and that there are significant differences in patient outcomes between age groups. They also concluded that their study is “highly supportive of surgery at a young age.” Do the data and results support the conclusions?

Most importantly, we recognize that tethered cord syndrome (TCS) or TCR surgeries in this particular administrative database are challenging to identify with ICD-9-CM diagnosis and procedure codes. Shweikeh et al. stated that they studied patients with the primary diagnosis of TCS who were treated with spinal laminectomy. We reviewed our institution’s records to see how they compare to the authors’ methods.

The authors use the following ICD-9-CM diagnosis code: 742.59 (other specified congenital anomalies of spinal cord). They label this group as “patients with a primary diagnosis of TCS.” The authors then use one of the following 3 ICD-9-CM procedure codes to indicate that their selected patients had surgery for TCS: 03.59 (other repair and plastic operations on spinal cord structures), 03.09 (other exploration and decompression of spinal canal), and 03.4 (excision or destruction of lesion of spinal cord or spinal meninges).

We identified patients treated at our institution using these same codes: 742.59 and 03.59, 742.59 and 03.09, or 742.59 and 03.4 on hospital discharge data. We compared this list with patients in our surgeon-entered clinical database who underwent TCR surgery.

Using the ICD-9-CM code search algorithm, we identified 86 cases; 78 of the 86 patients (90.7%) had some form of TCR surgery. However, there were 118 TCR surgeries in total in our prospective surgeon-collected clinical database, which is the gold standard of our practice. The sensitivity of the ICD-9-CM code search algorithm among patients with confirmed TCR surgery at our institution was 78 of 118 (66.10%). Forty of our confirmed 118 TCR surgeries were not identified by the ICD-9-CM code algorithm used by Shweikeh et al. Both ICD-9-CM and clinical database cases included diagnoses entered in our database of fatty filum, tight filum, TCS, dermal sinus tract, lipoma, lipomyelomeningocele, tumor, arachnoid cyst, atretic meningocele, and diastematomyelia. Indications included syringomyelia, scoliosis, neurogenic bladder, lower-extremity symptoms, and other clinical symptomatology. Six patients ranging in age from 5 to 15 years had reoperations, which added to surgical complexity. Of note, the typical practice at our institution does not tend to include prophylactic surgery, such as fatty filum sectioning for incidental radiographic findings.

A known limitation in administrative database studies is often a lack of clarity in surgical indications. For TCR, this is an important issue. Practice variation exists in the threshold for offering surgery.¹² Without the ability to identify the clinical indications, it may be spurious to draw conclusions about optimal timing of surgery or optimal candidates for surgery. The KID database does not offer enough information in this regard. Reoperations versus first-time surgery cannot be distinguished. Complications or sequelae diagnosed after hospital discharge are not recorded. The specific pathology associated with the label of TCS, or in the case of the study at hand (742.59, other specified congenital anomalies of spinal cord), is not known. Preoperative and postoperative levels of function are not known. For instance, the authors noted that older patients had a higher risk of nonroutine discharge, longer hospital stays, and complications than younger children. It is bold to conclude that surgery should be performed at a younger age without a lot more information. There are different populations who can fall into the highly heterogeneous cohort assembled by Shweikeh et al. Would it be fair to compare symptomatic teenagers having repeat lipomyelomeningocele surgery to infants undergoing prophylactic fatty filum sectioning?

We cannot be confident, based on our attempt at validation in our institution’s patient population, that the authors’ ICD-9-CM code algorithm actually studies TCR surgeries in a reliable or clinically meaningful way. We advise the utmost caution in drawing any conclusions about outcomes, disparities, or utilization using Shweikeh et al.’s study.

In summary, without correlation with clinical practice, assumptions in this study may be misleading. There are known limitations inherent to this type of research. Acknowledging these limitations openly and fairly is valuable for all readers. Vigilant study design and data interpretation are crucial.

We urge readers to be critical and to have an open mind at the same time. We support big data research and support development of the field to make it useful to all. Part of this process is to learn what works and what is not possible with administrative data studies. For example, we need to examine codes in detail and aspire to validate them with institutional clinical data in the study process. A large amount of work needs to be done. This study on TCR surgery provides an opportunity for learning what works and what should be reexamined carefully.

The field of pediatric neurosurgery has not reached maturity relative to other specialties with big data research. We encourage the pediatric neurosurgery community to keep the dialogue open and work together to build a deeper understanding regarding the role of this research.

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References

Disclosures
The authors report no conflict of interest.

Response
We appreciate the valuable comments and summary of our work by Drs. Lam, Pan, Jea, and Luerssen with regard to our use of the KID to study disparities in clinical and economic outcomes in children and adolescents following surgery for TCS. Studies based on the KID are prevalent in the pediatric neurosurgical literature.\textsuperscript{1–3} We recognize and fully acknowledge the limitations inherent in administrative databases, and, specifically with the KID, related to coding. However, despite the obvious limitation, the KID is the only all-payer pediatric inpatient database containing information relevant to pediatric neurosurgical operations. The KID provides a large sample size that tends to yield estimates with much smaller standard errors when compared to smaller databases.\textsuperscript{4} Without a sample of several million, as provided by the KID, estimates for less common procedures and diagnoses are unreliable and often unavailable.

The criticisms raised by the authors in their letter are certainly valid, and we appreciate their in-depth review of our paper, especially the comparison of their institutional data to that which we gathered from the KID. The fact that there were differences in the 2 data sets is concordant with the idea that the KID provides national and regional estimates of hospital inpatient stays by pediatric patients, enabling analyses of relatively rare conditions, such as tethered spinal cord, and the treatments offered. It is not unexpected that statistical analysis of the KID could lead to some conclusions that may differ from an individual or institutional practice. These differences enhance the literature and demonstrate that regional variations in care exist.

It is our belief that, despite limitations, there is value in analyzing administrative databases. It is our hope that pediatric neurosurgeons will continue to collaborate and create multistitutional databases to not only increase the sample size of various studies, but also to showcase regional variations in care. Peer review of outcomes in the context of these variations could lead to the designation of best practices for specific disease conditions encountered by all pediatric neurosurgeons.

References

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