Clinical Decision Rules for Epilepsy Care: The Case for Thinking Big

Main text page count: 2
Main text word count: 742
Character count of title: 68

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The goal of epilepsy clinicians is to provide high quality epilepsy care—the right treatment, to the right patient at the right time, and in the right way to achieve the best possible result.[1] Epilepsy is not a condition per se but a spectrum disorder,[2] which vastly complicates clinical decision-making. Usually identification of these “rights” is guided by evidence. One approach is development of clinical practice guidelines, which have proliferated over the past 20 years. Another approach for a more focused area is the development of clinical decision rules.[3] A decision rule based on data, and validated by additional study, can provide clinicians with much needed guidance when it comes to whether to conduct a diagnostic study, if and when to start a treatment, and which treatment generally works best for a patient with specific personal or clinical characteristics. While focused guidelines have been developed using literature review and expert consensus processes,[4–8] few clinical decision rules have been developed for epilepsy.

In this issue of *Epilepsy and Behavior*, Dr. Josephson and colleagues conducted a systematic review of the literature to identify all epilepsy focused clinical decision rules, and perform a meta-analysis where possible.[9] Careful evaluation of the literature revealed five articles describing four clinical decision rules. Three clinical decision rules focused on diagnostic issues, and one focused on treatment. Diagnostic clinical decision rules included a tool to identify nocturnal frontal lobe epilepsy vs. sleep disorder, a tool to identify critically ill children who would benefit most from continuous EEG monitoring, and a measure that identified children with epilepsy that are most likely to have abnormal CT scans. The single treatment clinical decision rule was a model that calculated a score based on age of seizure onset, seizure type, and EEG abnormalities to identify children who have a low risk of seizure recurrence after discontinuing antiepileptic drug therapy. Unfortunately, only two of the clinical decision rules

underwent validation allowing for meta-analysis. Even, then the findings for the nocturnal frontal lobe epilepsy measure led to questions about generalizability of the small combined sample (N=133).[9]

This paper provides several compelling insights. First, while clinical decision rules are guiding clinicians in other specialties, most notably emergency medicine[3,10] and cardiology [11,12] epilepsy lags behind in the development of these tools. Josephson and colleagues rightly point out that a number of methodologically strong prognostic models, such as the MRC Multicentre trial for Early Epilepsy and Single Seizures (MESS) that stratifies risk of recurrent seizures[13] and a nomogram that identifies risk of seizure freedom after epilepsy surgery[14] have been developed. These types of models are the foundation needed for the development of clinical decision rules.

Second they urge a pragmatic approach to developing clinical decision rules. Given that sound prognostic models exist, the community of epilepsy clinicians and researchers need to identify specific areas that would benefit from clinical decision rules, beginning with the areas where good prognostic models exist. Next, we need to identify areas where additional decision tools are needed. The most appropriate decision rules address a situation that is relatively common in clinical practice, where significant variation in practice exists, and where practice variation is associated with variation in outcomes[3]. Next data is required to develop prognostic models. Sometimes data from large administrative data sets can be used for those models. Existing guidance for epilepsy case-finding in large administrative databases provides a starting point that can be refined based on the purpose of the study.[15] But for some questions, clinically rich data will be required. If we want to achieve the goal of the Institute of Medicine Report, “To improve healthcare for people with epilepsy[2]” we need to think big—and harness “big data”

and “big collaborations.” Big data (e.g., claims data and data from electronic medical records) can be used to develop certain prognostic models using state of the art methods.[16,17]An excellent example the use of machine learning to identify antiepileptic drugs that would work best for patients with specific characteristics.[18]When more clinically rich data are required to develop prognostic models, multi-site studies will be required to acquire large enough samples to develop and validate methodologically sound clinical decision rules.

Ultimately, this important work cannot be achieved in “spare time” and will require funding. Existing mechanisms for funding epilepsy research focused on health services, pharmaco-economic, and outcomes research are limited, and generally cannot support the magnitude of work that is required. More creative funding approaches will be needed to accomplish this goal.

The author acknowledges and appreciates support from the South Texas Veterans Healthcare System/Audie L. Murphy Division. The views expressed in this article are those of the author and do not necessarily represent the views of the Department of Veterans Affairs. Mary Jo Pugh Receives support from VA Health Services Research 1I01HX000717-01, 1I01HX001056-01, and 1I01HX001304-01; the National Center for Complementary and Integrative Health (1R01AT008422-01), VA Rehabilitation Research and Development I01CX001246, 1I21RX002060-01; W81XWH-13-2-0095-04 and the Department of Defense W81XWH-13-2-0095-04.

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