Referring people with medically refractory seizures to an epilepsy center

It's not just for surgery

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Electronic practice aids appear in many forms. Some are on portable electronic devices, others on electronic medical records systems. Clinicians struggle to learn which tools are useful and reliable, and what role they should play in patient care.

In this issue of *Neurology® Clinical Practice*, Sauro et al.¹ evaluated a Web-based tool developed to help physicians determine which patients are appropriate for referral to an epilepsy surgery program. They described how the scope of their study prevented a more thorough examination of the tool's effect on clinical care and outcomes. They acknowledge that medically refractory epilepsy is complex, and many differences among patients would have to be controlled for. Simple tools do not always fit complex clinical situations. That is a challenge for software guidance.

This foreshadows how electronic health care records and information technology will influence neurology patient care in the future. We see here how physician-scientists struggle to define how to use IT tools as a guide. The developers engaged both experts in epilepsy and the generalist end users in the tool's development. The product remains a work in progress. Software brings information, but does it bring the right information?

There are 2 areas to consider here in which people with epilepsy are under-referred. One is the lack of referral for an epilepsy surgery evaluation. Surgery for epilepsy remains underutilized despite being an accepted, effective intervention.²⁻⁴ The second area is the lack of referral to epilepsy centers for a broader escalation of care and review of the care plan. This tool's focus is on the lack of presurgical referral, but it overlooks the broader need to refer medically refractory patients with epilepsy to a full-service (level 3 or 4) epilepsy center. While diagnosis and treatment at a full-service epilepsy center are demonstrated to improve seizure control, fewer than 1% of patients with medically refractory epilepsy are referred. One reason may be the misconception that epilepsy centers only offer surgery.

Epilepsy centers offer a wide range of services beyond resective surgery.^{5,6} Specialized multidisciplinary teams recognize and address pseudopharmacoresistance associated with non-adherence, nonepileptic seizures, treatable underlying conditions, incorrect diagnosis of epilepsy syndromes, treatment with an incorrect or suboptimal drug or dosage, and contributing lifestyle issues. Mental health providers and social workers at epilepsy centers are specialized to recognize and address the psychological and social challenges experienced by people with epilepsy. Beyond resective surgery, full-service epilepsy centers provide access to vagus,

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trigeminal, and deep brain nerve stimulation tools as well as responsive neurostimulation. Dietary treatment with a ketogenic or Atkins diet is available from specially trained dietitians.

Software tools are here to stay. Neurologists and other physicians should become accustomed to seeing various tools in their electronic health care records systems. Well-designed tools will offer well-designed guidance to prevent medical errors and to suggest diagnostic and treatment choices. These will need to be updated regularly to stay current with evidence-based medicine and with community opinions where specific evidence is lacking. The tools, in giving suggested directives, should avoid misimpressions and unduly limited choices. For patients with medically refractory epilepsy, tools designed only to help general neurologists identify surgical candidates may help with the lack of referrals for surgery, but may perpetuate a counterproductive belief that epilepsy centers only do surgery. A better tool would start with epilepsy center referral, which could make decisions there about whether surgery is warranted. Patients with epilepsy who have failed control with 2 medications, or who have other qualifying conditions, deserve a referral to a higher level of care available at a full-service epilepsy center. For patients who cannot afford to travel to an epilepsy center, telemedicine may serve a role. Software can serve up reminders, or help in prioritizing for such a referral. Software systems will continue to undergo refinements toward better reminders.

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