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Who's responsible to refer for epilepsy surgery? We all are!

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Epilepsy is not a benign disease. Patients with uncontrolled seizures face a trifold higher mortality risk compared with the general population and a yearly 0.5% risk of sudden death.¹ A patient's only chance to reduce this risk is by completely eliminating seizures. For those fortunate enough to be candidates, epilepsy surgery is an important treatment option, but growing evidence supports that many patients receive neither the necessary information about whether they are surgical candidates, nor an unbiased assessment of the risks of continued seizures vs surgical therapy. Theoretically, best practice dictates that many patients fulfilling criteria of being treatment resistant (failure of adequate trials of 2 antiseizure medications)² should be referred for a comprehensive epilepsy evaluation that might include epilepsy surgery. The current reality is that on average, adult patients who do get surgery have had intractable epilepsy for 20 years or more, and many who come for evaluation never knew they might be surgical candidates. Causes of this treatment gap are obviously complex, but may be summed up as a “knowledge gap” and a “feasibility gap.”

THE KNOWLEDGE GAP Three recent surveys,^{3–5} and one published in this issue of *Neurology*® by Roberts et al.,⁶ support that the primary treating neurologist's knowledge on what constitutes medically refractory epilepsy and when to refer is inaccurate. The authors surveyed practicing neurologists in Canada about their attitudes toward identifying and referring prospective patients for epilepsy surgery. Close to half of those surveyed responded, which is higher than previous surveys. The findings are very sobering: 57% of neurologists required patients to have drug-resistant seizures *and* to have at least one seizure per year before considering surgery, and nearly half (48.6%) failed to correctly define drug-resistant epilepsy. This misinformation persists despite publication of evidence-based guidelines by the American Academy of Neurology recommending referral for a surgical evaluation for drug-resistant seizures regardless of seizure frequency,⁷ and expert

recommendations by the International League Against Epilepsy that define refractory epilepsy as failure to respond to 2 adequately tried medications.² The guidelines and practice parameters are therefore available and clear. It is our responsibility as physicians and neurologists who care for people with epilepsy to provide this type of information, and to follow best evidence practices. Otherwise, we are exposing patients to continued seizures: less than 5% of patients with a positive MRI and failure of 2 antiseizure drugs become seizure free with continued medical therapy⁸ and delaying surgery may worsen the chances of long-term success by more than 40% in the most challenging group of frontal lobe epilepsy.⁹

While patients have some responsibility for their epilepsy, the greater burden falls on us, the epilepsy professionals. It should be the responsibility of epilepsy experts to disseminate guideline and expert recommendations to nonexpert professionals, patients, and caregivers with better tools of communication. These efforts require us to better understand dissemination barriers and to obtain feedback on what works in getting this information to consumers.

THE FEASIBILITY GAP More than 75% of neurologists surveyed by Roberts et al.⁶ identified inadequate health care resources as the greatest barrier to epilepsy surgery. Although 86.5% of those surveyed reported they had access to adequate expertise, the majority reported concerns about temporal and physical barriers to access. It is difficult to quantify how many of these access challenges are specific to the Canadian health system, but one would expect that the health care system within the United States, particularly given its continuously evolving landscape, would face similar challenges as reported in the recent Institute of Medicine report.¹⁰ This feasibility gap remains a particularly vexing and an especially underrecognized challenge. It is our responsibility as epilepsy providers to advocate for our patients and spend serious efforts to understand and improve access to care in our communities.

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Provider surveys are “pulse checks” that come with limitations. Half of the recipients of the Roberts et al. survey did not respond. Nonresponders differed substantially from the others: they were older, so presumably less exposed to recent guidelines and less facile with modern tools of knowledge dissemination; and they lived in a different geographic distribution, so presumably deal with different streams of access to care. As such, the nonresponders may be exactly the group that we need to understand better if we are to make a difference. This understanding requires a direct dialog rather than assuming opinions about their lack of engagement and their barriers from their silence, as is usually done in surveys, including this one.

In conclusion, best practice should be uniformly applied in a timely manner for all patients with treatment-resistant epilepsy. Ultimately, we are all responsible for delivering this best care to our patients, and necessary efforts go beyond education to include true collaborative initiatives at all levels of our social and health care structure.

AUTHOR CONTRIBUTIONS

Lara Jehi, MD: drafting the manuscript for intellectual content. Gary Mathern, MD: revising the manuscript for intellectual content.

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