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GUEST EDITORIAL

Specialty care for patients with epilepsy must become standard of care

Epilepsy is a complex, common disorder with severe consequences for patients. The authors believe that a significant percentage of patients are receiving suboptimal care. The national standard of care needs to be upgraded to include the notion that patients with less than total seizure control or those suffering from any medication side-effects should be given the opportunity to receive specialty care by physicians with specific expertise in the field of epilepsy.

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PROLOGUE

This editorial was originally submitted to ‘Neurology’ and ‘Archives of Neurology’. As mentioned below, we thought we were preaching to the converted. However, both journals declined to publish this, one recommending a specialty journal. We also submitted it to the ‘New England Journal of Medicine’ with identical results. It was also declined by ‘Epilepsia’.

This article is meant to start a dialogue. If there is no obvious consensus among ourselves, then it is futile to carry this further. However, a silent majority could also kill this proposed paradigm shift. The authors are willing to act as a clearing house. Let us know if you approve, or do not approve.

EDITORIAL

There are millions of people with epilepsy in this country (USA), and the majority are cared for exclusively by primary care providers. This trend seems to be increasing despite the increasing sophistication and complexity of epilepsy care, and the abundance of neurological specialists (a term meant to be inclusive of multiple types of care providers with neurological expertise). Although increased pressures on cost containment through managed care and third party and government reimbursers is obviously one factor, a more subtle and pervasive cause seems to be the real problem: neurological specialists have abrogated their role as ‘primary care’ providers for neurologic disease. The purpose of this article is to enjoin neurological specialists and their respective professional societies

to reconsider their actions, at least with regards to care for patients with epilepsy.

How many heart attacks should your patient have before they are referred to a cardiologist? How many episodes of gastrointestinal hemorrhage should a patient have before they are referred to a gastroenterologist? How many suicide attempts should a patient have before they are referred to a psychiatrist? In this spirit, how many seizures should a patient have before they are referred to a neurologist?

As a physician, would you send your own child or spouse to a traditional primary care provider after they had a seizure? And if not, do you have two standards of care—one for your patient, another for family and friends?

These are blunt questions, but necessary to expose the subtle, and erroneous ideas most physicians, insurance payers, and the public have about epilepsy. We hope we are preaching to the converted but a paradigm shift such as we are proposing has little precedent, especially if done by fiat. It certainly failed in the United Kingdom. In January 1996, the National Health Service Executive for England and Wales asked both purchasers and providers to work towards best practice of care for epilepsy. In a survey by the British Epilepsy Association¹ they found that services and care had actually become worse since the letter.

The spectrum of epilepsy’s impact on a person’s physical and mental health has been thoroughly reported and is well known to neurologists (the complexity of making an accurate diagnosis between real and pseudoseizures, and between seizure types; of choosing among a dozen drugs and surgical procedures; of educating patients about birth control and preg-

nancy, driving laws, and discrimination). Expounding the virtues of a neurological specialist over the primary care specialist has been done, and has failed to alter the referral patterns of primary care physicians. Any non-neurological physician will immediately concede that this is an area beyond his or her expertise. Why then do they continue to provide primary care, and preclude secondary care, for their patients? Is it financial, political, or is specialty referral just not accepted as appropriate? Such practice is not community standard of care!

The Promotion of Specialty Care for Epilepsy Group has grappled with this problem and has tried to address what our profession might do in response to these issues? The Group has tried to be sensitive to the many voices in society which may have both positive and negative reactions to changing the status quo. One response could be that there are not enough neurological resources (i.e. neurologists) to care for these millions of people, so leave the issue moot. However, if we really think we can provide better care, and that patients should expect to have treatment changed when it fails (after months, not decades), and that being seizure free without physical, mental or financial side-effects for a lifetime is the only goal, then we should train more neurological specialists. Here are some further thoughts.

Prevention

Most of medicine is focused on acute and chronic care. Treating patients after their first seizure needs to be aggressive to prevent the long-term consequences of epilepsy. Of patients who continue to have seizures for more than a year, only 60% subsequently achieve complete seizure control. Thus aggressive early treatment needs to be translated into 'community standard care'.

Legal

Is health care a right? This is being debated by Congress, the States, and the public. But a recent Supreme Court ruling said schools must provide extensively to the care of disabled students. For patients with seizure disorders, this should include speciality care. Physicians and their professional societies must make it clear that the physician's role to the patient comes first, and that we endeavour best care for all patients.

Malpractice

Who better to change expectations and rules than the organizations which pay the bills, or litigate. The state

malpractice carrier in Colorado has organized physician seminars outlining what is acceptable and unacceptable care. When might an epilepsy patient considering suing their doctor or health insurance carrier for not referring them in a timely manner to a specialist?

Driving

Epilepsy has a unique position between the rights of the individual and the privileges granted by states to operate a motor vehicle. By fiat, we may appeal to each State's department of motor vehicles to require a neurological specialist to review and approve reinstatement of a driving license. This is already being considered in Maryland. An extension of this approach would have states requiring that all epilepsy patients who want to drive be under the care of a specialist.

REFERENCES

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EDITOR'S NOTE

Although the authors were unable to get their paper published in an American Journal, I thought it of sufficient interest to publish it in a mainly European Journal, as there is a current Europe-wide debate about epilepsy services and, with the shortly to be published UK CSAG report on epilepsy services, I hope this guest editorial will promote discussion on both sides of the Atlantic. Debate, hopefully, will lead to an agreed course of action: if we specialists in epilepsy are convinced that we provide better care we may have to prove it and should also debate the best way of doing it.

Tim Betts