

## **THE CASE AGAINST PRACTICE PARAMETERS AND EVIDENCE-BASED GUIDELINES**

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The allure of “evidence” is irresistible to scientists (and I include physicians in that group). After all, there is evidence that proves carotid endarterectomy superior to medical management in some circumstances, that aspirin is more safe and effective than warfarin to prevent a second stroke, and that warfarin is the treatment of choice to prevent brain embolism in nonvalvular atrial fibrillation. Well and good. However, the majority of neurological situations requiring decisions by neurologists have not been and probably never will be studied in controlled trials. There is no evidence, and probably never will be, to govern the majority of decisions that must be made in treating patients with neurologic disease. Even if there were, guidelines could never take into account the many variables that occur in individual patients that affect clinical decision making, and new developments that affect decisions. For example, there are patients with nonvalvular atrial fibrillation who should not be taking warfarin e.g. those that have frequent falls. Guidelines embody the notion that neurologic care can be reduced to a cookbook full of recipes for handling clinical decision making. For the reasons mentioned, it can't.

Of more concern for the specialty of neurology are the practice parameters, advisories, and guidelines that are published by our own organization, the American Academy of Neurology. Please bear with me while I discuss why I am concerned. First, neurology as a specialty continues to be almost invisible to the general public. Many people don't know who we are or what we do. Your next door neighbor thinks you are a brain surgeon. (If you don't operate on peoples' brains, what DO you do?) Our own neurological organizations including the Academy have done a poor job of informing the public, health agencies, the federal government and even patients about who we are and what we do. We are not on any radar screen. Other specialties are far more visible and therefore influential. Everyone knows what a radiologist is and what he/she does.

The radiologists promote themselves and their specialty. Hospital accrediting agencies have rules that say if you don't have a radiologist you can't have a hospital. The rules say nothing about a neurologist. These events have affected reimbursement for neurologic services. It is literally true that a dermatologist's reimbursement for removal of a wart is twice as high as a Medicare payment to a neurologist spending an hour seeing a new patient with Alzheimer's disease. And if the neurologist happens to order an MRI on the patient with Alzheimer's, the radiologist will be paid two and half times more than the neurologist for the five minutes it takes to read and dictate the MRI. The obvious inequities involved in reimbursement schemes are beyond the scope of this syllabus but the fact is that reimbursement for evaluation and management codes in neurology are obviously poor and will get worse (a 5% Medicare cut in 2003). This is changing the practice of neurology. Neurology is a specialty that traditionally relied heavily on clinical input (history taking, neurologic exam, reviewing laboratory data including imaging, and communication with the patient and family on diagnosis, prognosis, testing and management.). The interaction of the patient with the neurologist is the most important aspect of treatment of that patient. Increasingly, it is an interaction that is being curtailed or omitted because it is economically not feasible for the neurologist. In order to pay overhead neurologists have turned to pursuits likely to generate more income e.g. procedures like EMG, botulinum toxin injections, other injection therapies, attending on stroke rehab units and nursing homes, doing pharmaceutical company - sponsored clinical research, and medicolegal work. Not one private practice neurologist with whom I spoke to prepare this syllabus is practicing only old-fashioned, good for the patient, E and M Code neurology.

The leadership in neurology is rightly criticized for failing to defend the specialty from inadequate reimbursement and also for allowing potentially remunerative areas to be captured by other specialties, e.g. neuroimaging.

Unless these economic factors are addressed, they will inevitably deter young physicians from choosing careers in neurology, despite the inherent fascination of the field.

How does all this relate to the Academy's publication of evidence-based parameters, guidelines and advisories? I contend that these publications are not helping our patients and are hurting our specialty. More specifically the wording encourages non-consultation with neurologists for neurologic conditions and can and will be used by third parties as justification for denying payment for neurologic services. I have reviewed our published guidelines and will provide illustrative examples:

1. In most of the practice parameters the word "neurologist" does not appear, suggesting there is little value for the patient to ever be seen by a neurologist.
2. In most of the practice parameters other specialties (psychologists, speech and hearing specialists, developmental pediatricians, etc) are mentioned by name repeatedly.
3. In the parameters it is repeatedly bemoaned that "appropriate tools" for patient evaluations have not been developed, when neurologic consultation is really the appropriate choice.
4. The parameters imply that general physicians can carry out neurologic exams and evaluate things like language, mental function, cranial nerves, muscle tone and reflexes ( and thereby through implication that neurologists are unnecessary). It is clear that general physicians do not do these things reliably..5. The parameters overemphasize the value of standardized tests such as IQ testing for various conditions.
6. Because there usually is no evidence pro or con, the implication is that such-and-such is unnecessary (for example, neurologic consultation).

Let me give you some examples of how these guidelines let us down. I contend that every neurologist at this meeting, if unfortunate enough to have a child with autism, would have the child seen by a child neurologist and the child would have brain imaging.

Our own published guidelines say we should do neither.

I contend that a patient with ALS should have the diagnosis made by a neurologist. Our guidelines in management of ALS do not mention the word neurologist.

I suggest that a child with a first unprovoked seizure should be seen by a child neurologist. Our parameters do not recommend doing that.

I suggest that in the detection of early cognitive impairment and the diagnosis of dementia the neurologist should be involved. Our own parameters do not agree, but have several pages on the description and use of neuropsychologic batteries.

Many of the parameters do not even use the word physician, referring instead to health professionals and clinicians, which could include clinical nurse specialists and other "professionals."

Practice parameters should be for the purpose of improving the care of patients. The overly wordy documents we are producing are not helping our patients in many instances. They are written in a scientifically rigid format which excludes the heart of what it is to be a neurologist and to evaluate patients with neurological disease. I'm talking about experienced history-taking, eye contact, compassionate face-to-face

interactions, and reasoned clinical judgment. These are things that – like much of neurology – simply can't be reduced to a parameter. Our members must be realizing this because for the most part they don't bother to read the guidelines. However I'm afraid other people **will** read them. Rather than producing practice guidelines the Academy should be employing its finite resources to improve the care of our patients by supporting the practice of neurology and improving reimbursement for neurologic services so we can be paid for the essence of what it is we do as neurologists for the good of our patients. There have been attempts to improve neurologic code reimbursement but these attempts have been marginally successful. Neurology lost in the RVU nonrevolution which pretty much kept the "cognitive specialties" (neurology, general internal medicine, family medicine, Pediatrics and Psychiatry) down at the bottom of the reimbursement ladder, while the high earning specialties careened along with high reimbursements as they always had..Why is it so hard to place value on a neurologic consultation? Once, when I was an examiner for the American Board of Psychiatry and Neurology I was ushered into a room with a candidate and saw a patient sitting on an examination table. She had a certain look. Hadn't moved, hadn't spoken. I knew she had Huntington's disease. I don't know how I knew. There's a lot of that kind of thing in neurology, and a lot of that is critical to the care of our patients. You don't see it in parameters and it can't be counted in numbers. But it's there.

Everything in life is a paradox. It turns out to be the opposite of what you first thought. One of the paradoxes of neurology is that as a neurologist and a person you are able to give the most to those who are incurable. For some diseases it's easy to give a patient a pill and cure him or her, but ultimately it is not as satisfying and meaningful as working your way through problem after problem in a patient with an incurable illness. As an example, I saw a patient – a secretary – who came with her family. She had been diagnosed with ALS and she knew she was going to die. When I first saw her she was already in a wheelchair, but she hadn't stopped working. She made her boss build a ramp for her so she could get to work. Her family commented to me repeatedly how strong she was, how she never got depressed or cried and how positive she was about her life and her job. I began to see her about every three weeks. She would come into my office, and I would hold her hand and she would cry. She told me: "I have to be strong with them, but I need to see you so I can have a place to cry." She literally worked until the day she died of respiratory failure.

Parameter is a meaningless word (something to measure). The essence of neurology can't be reduced to parameters. Don't get me wrong. I'm all for evidence. There are important issues that need to be resolved for the benefit of our patients. I loved the trial that showed that TPA is effective in acute stroke. We need more studies like this. We need controlled clinical trials. But practice parameters can't create evidence that isn't there.

Reference

AAN Practice Handbook Update 2000-2001