ETHICAL PERSPECTIVES IN NEUROLOGY

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The practice of neurology presents a series of ethical challenges for the clinician. These rarely have simple or straightforward solutions, but require careful consideration by the neurologist. This section of CONTINUUM, written by colleagues with particular interest in the area of bioethics, provides a case vignette that raises one or more ethical questions related to the subject area of this issue. The discussion that follows should help the reader understand and resolve the ethical dilemma.

NOTE: This is a hypothetical case.

A 22-year-old man is referred for consultation for possible multiple sclerosis (MS). At age 19, he had subacute onset of blurring in his right eye, progressing to inability to count fingers. He also had pain with eye movement. His ophthalmologist diagnosed optic neuritis (ON) and treated with a course of IV steroids, consistent with the results of the Optic Neuritis Treatment Trial. (Volpe, 2008) His vision recovered to 20/50. One year later, he had an episode of ON in the left eye and was again treated with IV steroids. He had substantially less visual recovery; visual acuity was 20/400 OS at the time. He was not referred for neurologic evaluation by his ophthalmologist.

Troubled by his persistent visual impairment and with his family's urging, after 2 years, he sought a second opinion from a neuro-ophthalmologist, who ordered a brain MRI and subsequently referred the patient to you. The MRI showed two to three small peripheral nonenhancing lesions.

On examination, he is a healthy appearing man. Visual acuity is 20/50 OD and 20/200 OS. Funduscopic examination shows pallor bilaterally. He also has mild spasticity of the lower extremities with hyperreflexia and extensor plantar reflexes. While the clinical data are consistent with MS, laboratory testing for neuromyelitis optica (NMO) immunoglobulin G (IgG) is positive. MRI of the cervical and thoracic spine demonstrates a T2 hyperintense lesion extending from C3 to C7. These findings and the diagnosis of NMO (Devic disease) are reviewed with the patient, and treatment with azathioprine is recommended.

The patient becomes upset and angry and asks why the other doctor did not diagnose him properly. He says he knew something was wrong with him and asks directly if his visual loss could have been prevented with earlier treatment.

DISCUSSION

▶ When patients become upset and ask their neurologist why *another* physician did not make a diagnosis or initiate a therapy, the neurologist can be in a quandary. Often

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embedded in the patient's anger are implicit questions, such as whether earlier diagnosis or treatment would have reversed the clinical course or prevented progression of the disorder, which ultimately raises the question of whether the first physician's care fell beneath the standard of care and might constitute malpractice. The neurologist's answer to such a question should be carefully considered and based as much as possible on the factual aspects of the case while being mindful that the neurologist is balancing several ethical and professional issues, including telling patients the truth, avoiding disparagement of colleagues, and respecting patients' rights to seek redress if harmed. In this case, the clinical presentation of recurrent ON with no other symptoms and a brain MRI with T2 hyperintense lesions are consistent with MS. However, the positive NMO IgG testing along with myelopathic signs and a longitudinally extensive spinal cord lesion on MRI makes the correct diagnosis NMO. The neurologist must consider the similarities and differences in clinical presentation, treatment, progression, and outcome between these two entities when responding to the patient.

RESPONSIBILITY TO THE PATIENT

▶ The physician-patient relationship relies (Beauchamp and Childress, 2001) on the trust that the patients place in their physicians' hands to protect them and act in the patient's best interest. In part, physicians demonstrate respect for patients by providing them with accurate and adequate information they may need to make decisions regarding their health care. Respect for a patient's autonomy, which encompasses, among other things, their emotions, privacy, and right to seek compensation, is a fundamental bioethical principle. In this instance, before the physician responds, there is a need to review the current medical evidence.

NMO is an autoimmune, demyelinating condition with preferential involvement of the optic nerves and spinal cord. Unlike typical MS, NMO is often rapidly disabling. Early in the disease, over half of relapsing patients with NMO become monoplegic or paraplegic, and most become legally blind.(Wingerchuk et al, 1999) Acute attacks are often treated with high-dose IV steroids. Existing data suggest that plasmapheresis is a useful treatment option for patients who do not improve with steroid therapy (Ruprecht et al, 2004; Weinshenker et al, 1999). No randomized controlled trials of NMO have been undertaken, but evidence suggests immunosuppression is more effective than interferon treatment for long-term preventive therapy (Papeix et al, 2007; Warabi et al, 2007; Wingerchuk and Weinshenker, 2005). Despite variable efficacy and outcomes, azathioprine (Mandler et al, 1998), cyclophosphamide, rituximab (Cree et al, 2005), and mitoxantrone (Weinstock-Guttman et al, 2006) have been investigated and can reduce relapse rates. Given its potential for neurologic disability, most neurologists would initiate some type of long-term immunosuppressive treatment for NMO at the time of diagnosis.

Although physicians are often asked why a diagnosis was not established sooner, the question is problematic. MS and other demyelinating conditions are difficult to diagnose early in their course, and several years may separate symptoms. Unfortunately, the underlying neurologic disorder may progress subclinically or radiographically in the interim. Trying to separate whether or not an earlier diagnosis would have prevented future neurologic disability is only answered in cases wherein treatment has been established to be highly successful at managing the condition or is

curative. In NMO, no such treatment is available. In this case, however, a second episode of ON and the refractoriness to IV steroids should have triggered further investigation or a referral.

PROFESSIONAL RESPONSIBILITY

▶ Before sharing concern with the patient, the neurologist should communicate with the original ophthalmologist to review the case. Assumptions about what the ophthalmologist was thinking or not thinking are purely speculative. Multiple relationships are at risk; blaming other physicians undermines one's own professional integrity, may influence how patients perceive their physicians, and will certainly impact the relationships with other professionals. The AAN Professional Code of Conduct addresses this very issue: "The neurologist should not unjustifiably criticize a colleague's judgment, training, knowledge, or skills" (AAN Professional Association, 2008).

That being said, physicians likely have a tendency to protect other physicians. The profession also has an ethical responsibility to "help improve its quality" (Smith et al, 1999). The neurologist can review the details of the case with the ophthalmologist and share the eventual diagnosis of NMO. A phone call represents an important, private opportunity to open a dialogue through which the ophthalmologist may become more familiar with the condition. This communication would require the patient's and family's permission and would likely alleviate some of their distress and concerns. Although US Health Insurance Portability and Accountability Act (HIPAA) regulations (45 CFR 164.506) (US Department of Health and Human Services) would allow the neurologist to communicate with the ophthalmologist without the patient's permission, as a matter of courtesy and propriety in a circumstance where the patient is upset with the ophthalmologist, it would be wise to obtain the patient's permission to do so. Given that the primary responsibility for the error rests with the ophthalmologist, that physician has a professional responsibility to discuss this directly with the patient.

Medical Error

▶ Physicians are required to provide a standard of medical care consistent with their expertise and training (AAN Professional Association, 2008). Substantial recent interest in medical errors, patient safety, and apologies has emerged in the public media and the medical literature. For the purposes of this case, it is relevant to review some definitions. Medical errors are defined as failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim. Adverse events are injuries caused by medical management rather than the patient's underlying disease (Kohn and Corrigan, 2000). In this context, this case represents a lack of appropriate testing/referral and medical error, a missed diagnosis, on the part of the ophthalmologist. From a legal standpoint, a missed diagnosis may or may not represent malpractice. In neurologic malpractice claims, "failure to diagnose" is the most commonly cited medical error, in some cases 50% to 60% (Glick, 2001). Malpractice requires four elements: (1) the existence of a physician-patient relationship, (2) practice below the standard of care, (3) harm to the patient, and (4) direct causal link between the substandard practice and the harm. Determining whether this case represents malpractice is not the treating

neurologist's responsibility and is beyond the scope of this article, but given the evidence, causality would be difficult to ascertain in this case.

Although little research about how to handle disclosure of mistakes made by another physician is available, research on how to handle one's own mistakes may provide some guidance and insight. Research on medical errors indicates that patients want to know the truth about *all* medical mistakes (Mazor et al, 2004; Witman et al, 1996). However, research also suggests physicians are less likely to disclose errors that are not readily apparent to patients, a practice inconsistent with standards from the Joint Commission (formerly Joint Commission on Accreditation of Healthcare Organizations) (Gallagher et al, 2006; Joint Commission on Accreditation of Healthcare Organizations, 2001). Conversely, adopting truth telling as a practice solely because of fiduciary responsibilities to patients misses an opportunity to deliberate and reflect on the needs of individual patients and circumstances (Barilan, 2009). Although most physicians also support the concept of disclosure, multiple perceived barriers exist (Finkelstein et al, 1997; Novack et al, 1989). Before disclosing an error, some authors advocate determining whether the error failed to meet a standard of care, whether treatment would have changed, and whether the physician would want to know of a similar type of error in their own care or that of a relative (Boyle et al, 2006).

When disclosing a medical error, key elements should be included: a statement of the medical facts, an apology, and the plan to prevent future similar events. An apology should involve remorse or regret, eg, "I'm sorry about what happened," and may involve a more direct statement of the error and its consequence (Gallagher et al, 2006). Keep in mind that different states and hospitals may have laws or policies regarding preferable approaches. A person of authority should make the disclosure (Williams and Rushton, 2007), which may mean that the person directly responsible is not the one guiding the disclosure. Despite physicians' fears of lawsuits, a growing body of literature supports the assertion that apologies may prevent litigation (Mazor et al, 2004; Mazor et al, 2006; Robbennolt, 2009; Witman et al, 1996).

In bioethics, truth telling and honesty are key components of respect for persons. Not being honest, whether by omission, "finessing" details, or frank lying, involves some degree of deception and undermines trust. Given the variables of this case, the ideal response of the neurologist is to empathize with the patient's experience, to communicate a willingness to discuss further with the ophthalmologist, and, most importantly, to be honest about the uncertainties, which include whether earlier diagnosis or treatment would have definitively altered his clinical course. Respecting patient autonomy in this case means conveying to the patient what is known about the diagnosis, as well as the advantages, efficacy, and potential shortcomings of immunosuppressive therapy. If the patient expresses concern about the fact that the ophthalmologist apparently did not consider NMO, an appropriate response would be, "I can't say, but I will explain my own thoughts to your ophthalmologist. I would suggest you discuss your concerns further with him." The neurologist cannot avoid the conversation in the hope that someone else may have it. Physicians should not offer opinions based on limited data and should speak within their expertise (and not beyond).

The practice of medicine is inherently fallible in that it is practiced by human beings. Neurologists and health care professionals should understand that truth telling is an active dialogue between two "moral agents" with their own principles and values (Gold, 2004). One cannot simply decide what or how much is best for the other.

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