THE PROFESSION OF NEUROLOGICAL MEDICINE

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My remarks, which are meant to stimulate discussion over the next few hours of this symposium, are divided into four sections: definitions, a case presentation, some comments about professionalism and a few general principles about academic neurology and patient education.

Part I: Definitions

Education, from the Latin root meaning a drawing forth, implies not so much the communication of knowledge as the discipline of the intellect; an intra-cerebral process aimed in large part at creating principles upon which new knowledge may be elaborated. *Instruction* is that part of education that furnishes the mind with knowledge. *Teaching* is often applied to practice as in "teaching a dog to do tricks." *Training* is an element of education in which the chief characteristic is exercise or practice for the purpose of imparting facility, as in "training for the marathon." *Breeding* relates to manners and outward conduct as in "standing when elders enter a room is a sign of good breeding."

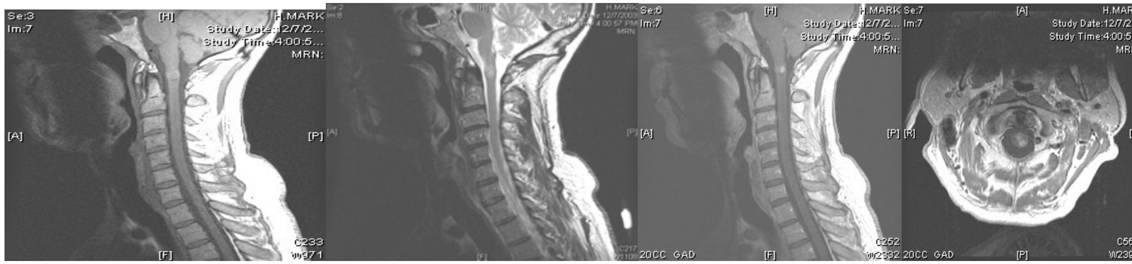
Regimentation is the prescription of a particular way of life or thinking usually involving the imposition of discipline. The term, arising from military regiment, is related to the medical usage of regimen, as in "the patient keeps his prescription medications in separate compartments of a plastic container in order to accurately adhere to his regimen." *Propaganda* is the systematic propagation of a doctrine, cause or information reflecting the views and interests of those advocating such a doctrine or cause, as in "The authors of the Institute of Medicine report entitled *To Err is Human* are propagating the view that medical error is the major cause of death in the United States."

Part II: Case Presentation

A 30 year-old right-handed man comes for an additional opinion about increasing symptoms arising from a spinal cord lesion. He presented seven years earlier with paresthesias in the left leg. Evaluation at that time revealed a mass within the cervical spinal cord at the level of the odontoid process. The lesion was judged to be inoperable. Over the intervening years the lesion has been followed with intermittent MRIs and has changed little, if at all, but the patient has suffered a slowly progressive deficit with worsening disability. He has sought opinions in neurology and neurosurgery at several major medical centers including The Mayo Clinic in Rochester, Minnesota, the Lahey Clinic in Burlington, Massachusetts and the Massachusetts General Hospital in Boston, Massachusetts. One neurosurgeon confidently told the patient that he had Von Hippel Lindau Disease and that the lesion was unequivocally an hemangioblastoma. Others had suggested an astrocytoma, while still others felt it was an ependymoma. None have believed that its clinical or imaging features were likely to be due to a syrinx. Repeated MRIs and medical evaluation have failed to reveal any other lesions in the spinal cord, brain, or the rest of the body.

Oral anti-spasticity medications have failed to yield any benefit. Several neuro-radiotherapists have been unwilling treat the lesion without a tissue diagnosis and no neurosurgeon has been willing to biopsy for fear of producing tetraplegia. Over the years the deficit has slowly worsened such that he now has severe spasticity of both legs, worse on the left and spastic weakness of the right arm. He has urinary frequency, some episodes of incontinence and erectile dysfunction. He continues to have paresthesias, now in both legs and the right arm, but has no sensory complaints on the trunk.

His examination now shows a normal mental state and cranial nerve examination. There is spasticity of all four limbs, left leg worse than right leg worse than right arm worse than left arm. There is no wasting or spontaneous muscle activity. Vibration and joint position sense are reduced to the knees but there is no level on the trunk for any modality. The Romberg test is positive. His gait is spastic. There are no cerebellar signs and the reflexes are dramatically increased with sustained clonus at the ankles, greater on the left, and he has bilateral Babinski signs.



The magnetic resonance images reveal an oval mass in the cervical spinal cord, that enhances incompletely with gadolinium.

In an effort to assess the available educational tools for utility in helping me to assess this patient's problem, I turned to several of the commonly used resources. In Up-to-Date I found a superficial listing of spinal cord tumors. The new strikingly beautiful Cecil Textbook of Medicine had no information on the subject. Neurology in Clinical Practice had a complete listing of spinal cord tumors, but was not helpful in determining the likely nature of this patient's problem or the diagnostic or therapeutic approach that might be rational. Conflict of interest prevents me from commenting on what I found in Office Practice of Neurology and the Manual of Neurologic Therapeutics, but I am prepared to tell you that they were not particularly helpful either. Searching the internet using Google yielded hundred of sites related to spinal tumors but not surprisingly nothing that could do anything but increase this patient's anxiety without shedding a ray of light on the approach one might take to help him. The patient himself had already taken that route to no avail. I shall let you contemplate what might be your approach to this problem while I make a few remarks about medical professionalism.

Part III: Professionalism

The Charter on Medical professionalism, which was published simultaneously in the Annals of Internal Medicine and the Lancet in February, 2002, was developed by a task force of the Medical Professionalism Project, sponsored by the American Board of Internal Medicine Foundation, the American College of Physicians-American Society of Internal Medicine Foundation and the European Federation of Internal Medicine. Chaired by my good friend and colleague from the Brigham, Dr. Troyen Brennan, the Medical Professionalism Project's Charter has been adopted by scores of medical societies in virtually every country in the world. I quote loosely from the Charter.

Changes in the health care delivery systems are threatening the inherent nature and values of medical professionalism, which is itself the basis of medicine's contract with society. The contract terms are fairly simple. In return for maintaining professional values, doctors are afforded a number of tangible benefits including financial reward, societal respect, access to the most sensitive and intimate information and broad freedom to carry out research, even involving other human beings.

Though inbedded in diverse cultures and national traditions, the basic role of healer that has roots extending back to Hippocrates, shares certain basic principles that are independent of variations in medical care delivery and practice. The Charter articulates three fundamental principles and ten supporting professional responsibilities.

The three principles are: primacy of patient welfare, patient autonomy and social justice. The ten professional responsibilities required to nourish and maintain the three principles are: professional competence, honesty with patients, patient confidentiality, maintenance of appropriate relations with patients, improving quality of care, improving access to care, just distribution of finite resources, scientific knowledge, maintenance of trust by avoiding conflicts of interest, and professional responsibilities.

Medicine is special because it is one of the learned professions. Like law, it is dependent on education in the real sense. Medical professionalism is defiled by regimentation and propaganda masquerading as education.

Part IV: Principles Gleaned from a Career in Medicine and Neurology

Diagnosis and adios is a thing of the past, but this change comes with significant risks. When the first edition of *The Manual of Neurologic Therapeutics* was proposed in 1975, the title was considered an oxymoron (akin to airline food and military intelligence). Now that neurologists are a target for pharma, they must become vigilant for becoming tools of industry. Overstating benefits of new treatments (eg stem cell therapy, thrombolysis, brain stimulation) is a cruel hoax that prevents people from confronting their mortality in a realistic and healthy fashion with the help of a professional physician.

The submarines are permanently submerged, but saying so is politically incorrect in the world of the elite academe. In the modern world of professionalized science (including neuroscience), no one can

perform cutting edge research while functioning as a gourmet clinician and effective teacher, much less understand enough of the principles of business and organizational leadership to keep a department off the radar screen of the cost conscious hospital administrators. Academic leaders must understand and foster the best clinical care, the finest basic and clinical research, andb the most inspiring teaching, while garnering the necessary resources to allow each to flourish. In a given era in a given institution, the leader may come from any of these sources, but trying to come from all of them will produce a transparent dilettante. Trying to validate the fantasy of the triple threat by demanding confirmation from those who are most impressionable and dependent (students and residents) produces a surrealistic Wizard of Oz world in which young people are forced to aspire to becoming "the man behind the curtain" in order to gain entrance into the guild. This leads to disappointment, cynicism and frustration as the next generation of neurologists find themselves failing to be able to live up to a distorted image of the "days of the iron men." The closer one gets to the giants, the easier it is to see their feet of clay.

The nervous system's interaction with the other organs is a legitimate specialty of neurology and medicine. As general medicine becomes progressively more complex, the need for understanding the neurological aspects of illnesses in other systems has become a major need. Neurologists who wish to specialize in these areas (eg cancer neurology, immuno-neurology, cardiovascular neurology, infectious and inflammatory neurology, gastrointestinal and hepatic neurology, hematoneurology, renal and electrolyte neurology) must seriously study the corresponding medical discipline in order to make important intellectual and clinical contributions.

Shifting professional responsibilities from doctors to patients is a dangerous act that stems from lack of confidence in the profession of medicine. There are many social forces that have fueled this loss of confidence, but one of the seminal moments was the ill-conceived and self-hating Institute of Medicine report entitled "To Err is Human," which grossly exaggerated the importance of error as a cause of death in the United States. This has led to an entire industry, populated by companies founded by the authors of the IOM report, to correct and prevent error. Hospitals have become obsessed with avoiding bad publicity in the lay press stemming from perceived failures to ensure patients' well-being. To facilitate this need by doctors and hospitals to avoid responsibility, patients have become encouraged to "take responsibility for their own care," endlessly searching the internet in a futile effort to learn medicine, a profession that should take an entire career to continuously perfect. This mentality is reminiscent of the flight attendants reminding passengers that their failure to "stow their carry-on items and taking their seats promptly" is really the reason that the plane is taking off two hours late. Blaming the victim and expecting the patient to sort out the myriad of medical data on the internet is a method for doctors to avoid responsibility for performing their own professional responsibilities. Information, no matter how it is stored, is not wisdom nor is it judgment. One who defends himself in court has a fool for a client. It is said that former President Jimmy Carter spent an entire weekend trying to understand the technical diagrams of the B1 bomber. Such an effort is futile and worse. It risks a dangerous error generated by a naïve understanding of a complex problem and de-professionalizes the work of the engineers. Should I spend my weekends reading number theory so that I can participate in a seminar in the mathematics department of the university? Shall I debate the cost-effectiveness of various types of spark plugs with my car mechanic? It is the physician's responsibility to study medicine and to be a professional. If my physician cannot integrate all of the relevant data and give me an opinion about what I have and what I should do about it, I need another physician. Patient involvement in their own care is fine provided it is not a veil for the shirking of the physician's professional responsibility.

Addendum: My opinion about the case

I believe the lesion is probably a very low grade astrocytoma, but could be another pathological process such as hemangioblasoma or even ependymoma. I discussed the options with the patient and his wife as well as the current spine neurosurgeon involved in his care. We are considering the possibility of an angiogram. If the lesion is quite vascular, it may be an hemangioblastoma which could be partially ressected safely. The risk of the angiogram is low but not zero, so a final decision about this has not yet been made. If the angiogram is not done, or if it shows a non-vascular lesion, I have recommended a baclofen pump to treat the spasticity, which is his most disabling symptom. We also discussed the possibility of using steroids, but decided for the moment to hold that therapy for future use. Some of his symptomatic worsening with a lesion that looks much the same over time could be due to his anxiety about the nature of the lesion and its probable natural history. By seeing him myself over the next couple of years, I should be able to resolve this question. For the moment, he and his wife seem to understand the plan and appear much less anxious and thus less predisposed to cast about searching for a magical cure.

The point of this case presentation was not to produce a miraculous and surprising diagnosis, but rather to illustrate the real practice of neurology and the kind of case based, information and judgment enriched

interaction that is likely to help the patient while at the same time providing the neurologist with a more satisfying truly educational experience and thus an enhanced professional life. Throwing difficult problems back in patients' laps is unprofessional.

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