Role of Professionalism in Improving the Patient-Centeredness, Timeliness, and Equity of Neurological Care

Christopher T. Bever Jr, MD, MBA; Gary M. Franklin, MD, MPH; Joel M. Kaufman, MD; Gregory J. Esper, MD, MBA

A 45-YEAR-OLD, MALE, Spanish-speaking day laborer with a 27-year history of epilepsy sees a new neurologist for advice regarding his medication and midback pain. Six months ago, he visited the emergency department regarding the pain because his primary care physician did not have late afternoon or evening office hours and he feared that if he missed work he would lose his job. Plain-film radiographs suggested osteoporosis, and he was advised to see a neurologist to change his medications. He has been receiving phenytoin for at least 20 years with good control but was never advised to take vitamin D or calcium. He reports that his previous neurologist performed an examination and checked laboratory values, but as there was no translator, the patient had difficulty understanding everything he was told. It took 6 months to arrange for the new appointment as few offices have translator services.

Author Affiliations: Neurology and Research Services, Veterans Affairs Maryland Health Care System and Department of Neurology, University of Maryland School of Medicine, Baltimore (Dr Bever); Departments of Occupational and Environmental Health Sciences, Neurology, and Health Services, School of Public Health and Medicine, University of Washington, Seattle (Dr Franklin); Department of Neurology, Warren Alpert Medical School at Brown University, Providence, Rhode Island (Dr Kaufman); and Department of Neurology, Emory University, Atlanta, Georgia (Dr Esper).

This case illustrates some of the serious problems facing patients with neurological diseases despite the fact that their neurologists are highly trained and dedicated clinicians who provide excellent care. This patient's care falls short in several areas. The care was not effective in that the patient had not received proper preventive care. The care was not timely in the sense that the follow-up visit with the neurologist was delayed. The care was not patient-centered in that it was being driven by resource limitations in the community rather than patient need. The care was not equitable in that the patient was not getting appropriate ongoing and follow-up care because of his limited English proficiency. As is common with many of the problems experienced by neurological patients, the problems in this case were largely system-level problems not under the immediate control of the neurologist.

The Institute of Medicine reviewed the serious and pervasive quality problems of the health care system in the United States in *Crossing the Quality Chasm: A New Health Care System for the 21st Century*[1] in 2001 and identified 6 domains of health care for improvement: safety, effectiveness, efficiency, patient-centeredness, timeliness, and equity. Formal efforts aimed at assessment of evidence related to safety and effectiveness have grown substantially in the past 2 decades with the development of guidelines and health technology assessments by medical specialty and other organizations.[2,3] Because of the burgeoning health care costs, efforts to improve efficiency have been a focus for government and private payers.[4] Improving the timeliness, patient-centeredness, and equity of care have received relatively less attention. While the physician's primary responsibility is to serve as the patient's advocate, the increasing influence of payers and regulators and the perverse incentives related to defensive medicine have undermined the physician's traditional role. Medical professionalism, broadly defined as "attitudes and behaviors that serve to maintain patient interest above physician self-interest,"[5] has been relegated to less prominence in the midst of these cost, overhead, and administrative burdens on physicians. Yet, along with prudent use of evidence-based best practices, professionalism is likely to hold the most promise within the control of the physician in delivering the type of accountable and integrated care that is reflected in the recently passed federal health care overhaul.[6] Patient-centeredness is a direct consequence of professionalism, and timeliness and equity are more indirect but potentially crucial outcomes.

MEDICAL PROFESSIONALISM

A number of formal efforts aimed at defining medical professionalism for medical students, trainees, and practicing physicians have been published (**Table**).[5,7-9] For example, the Medical Professionalism Project, a joint effort of the European Federation of Internal Medicine, the American College of Physicians, the American Society of Internal Medicine, and the American Board of Internal Medicine, included 10 professional commitments relevant to the im-

©2010 American Medical Association. All rights reserved.
Downloaded From: https://jamanetwork.com/ by a CDC – Center For Disease Control User on 04/18/2019

Table. Definitions of Medical Professionalism

Organization	Definition
American Board of Internal Medicine[5]	Core of professionalism: attitudes and behaviors that serve to maintain patient interest above physician self-interest; specific elements of professionalism: altruism, respect for others, honor, integrity, ethical and moral standards, accountability, excellence, duty, and advocacy
Association of American Medical Colleges[7]	Physicians should be altruistic, knowledgeable, skillful, and dutiful
Medical Professionalism Project[8]	Ten commitments: competence, honesty, confidentiality, maintaining appropriate relationships, improving the quality of care, improving access to care, the just distribution of finite resources, scientific knowledge, maintaining trust, and professional duties
American Academy of Neurology[9]	Attributes of professionalism: respect for the individual, treating the whole patient, understanding the patient's narrative, empathy with patients and their families, translating complex concepts into language that patients and families can understand, helping patients anticipate the future without undermining hope, maintaining a commitment to treat patients with chronic and intractable illnesses, and a commitment to high-quality palliative and end-of-life care

provement of the patient-centeredness, timeliness, and equity of care. Among these were improving quality of care, improving access to care, and the just distribution of finite resources.[8] In addition, the American Academy of Neurology Ethics, Law, and Humanities Committee offered 10 professional attributes they considered intrinsic to the practice of neurology.[9] Among those that are relevant to improving the patient-centeredness, timeliness, and equity of care were the following: respect for the individual, treating the whole patient, understanding the patient's narrative, empathy with patients and their families, translating complex concepts into language that patients and families can understand, helping patients anticipate the future without undermining hope, maintaining a commitment to treat patients with chronic and intractable illnesses, and a commitment to high-quality palliative and end-of-life care. The committee recognized that such attributes and values would be critical to maintaining the trust of patients, resolving conflicts of interest, and increasing personalized care. The economic pressures of the practice of medicine and the substantial rise in opportunities for external parties (insurers, pharmaceutical and device manufacturers, plaintiffs' attorneys) to influence physician behavior have likely been in conflict with serving patients' or the greater society's best interests; the American Academy of Neurology Ethics, Law, and Humanities Committee concluded that these factors may have caused a decrease in the application of the best principles of medical professionalism.[5] Both the recent health reform effort and the public's perception that poor (and declining) professionalism is correlated with poor care[7] provide a timely impetus to consider how the application of professionalism in neurology can address the mandates of the Institute of Medicine to improve the patient-centeredness, timeliness, and equity of care.

PATIENT-CENTEREDNESS OF CARE

For most of the past century, medicine has focused primarily on its most limited resource, the clinician.[1] The organization and processes of health care delivery have not been driven by the patient, except in the limited sense that patient medical needs were interpreted by clinicians. The experience of patient-centered care has been defined as "that of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care."[10] Patient-centeredness has been further defined with 8 dimensions: respect for patient values, preferences, and expressed needs, information and education, access, emotional support to relieve fear and anxiety, involvement of family and friends, continuity and security of transitions, physical comfort, and coordination of care.[11] These characteristics are what most neurologists would expect of their own care if they were patients.

Although the Institute of Medicine report identified patient-centeredness as an outcome of the health care system equal in importance to effectiveness, there is evidence that patient-centered care may improve medical outcomes. Grosset and Grosset[12] examined the relationship of patient-perceived involvement in decision making in the management of Parkinson disease and found a positive correlation with patient satisfaction with care and compliance intent. A study of family practice visits showed that more patient-centered communication by the health care provider was associated with better recoveries, improved emotional health, and the use of fewer diagnostic tests and referrals.[13] Patient-centeredness is an important outcome of the health care system per se that can improve medical outcomes.

TIMELINESS OF CARE

Most neurologists would agree that timeliness of care is important but would view it as such primarily because it improves other outcomes such as safety and effectiveness. The Institute of Medicine report defines timeliness as an outcome of health care in its own right.[1]

Delays in neurological care can be associated with worse outcomes. This is best documented in the management of acute stroke where delays limit the use of thrombolytic therapy. Several studies have identified sources of delays in acute stroke care[14,15] and have examined system changes to reduce those delays.[15,16] Another study identified delays in the scheduling of electrodiagnostic studies for work-related carpal tunnel syndrome as contrib-

©2010 American Medical Association. All rights reserved.
Downloaded From: https://jamanetwork.com/ by a CDC – Center For Disease Control User on 04/18/2019

uting to reduced potential for early return to work.[17] Anecdotal examples of delays in other areas of neurological practice leading to poor outcomes abound. Many of the causes of delays were not controlled by the neurologists but were related to other aspects of the care system. The neurologist, in many instances, can play a key role in identifying the causes of delay and advocating for changes that could improve the timeliness of care.

EQUITY OF CARE

Health disparities based on sex, race, socioeconomic status, and physical disability are widely recognized in medical care in general[18] and in neurological care specifically.[19] Studies of acute stroke care suggest that disparities exist related to sex (with longer "door to computed tomography" times in women)[20] and race (with longer "door to computed tomography" times in African American patients).[21] A study of the use of carotid endarterectomy found that patients belonging to racial minority groups were more likely to have inappropriate surgery.[22] Use of noninvasive positive pressure ventilation in amyotrophic lateral sclerosis, which improves survival, was found to be used less in patients with lower incomes.[23] A study of the management of bladder dysfunction in patients with multiple sclerosis showed that those without health insurance were less likely to receive evaluation or medications for bladder symptoms.[24] Non-Hispanic white patients with Parkinson disease were more likely to receive recommended treatment for depression than other groups.[25] A recent study of epilepsy care showed disparities related to ethnicity, income, and insurance coverage in access to subspecialty care, use of emergency department care, and hospitalizations.[26] Persons with disabilities may receive preventive care at lower rates as one study found lower cancer screening rates among disabled adults than among nondisabled adults.[27] Neurologists must be aware of these and other potential disparities in the equity of care so that they can advocate for their patients. The external economic exigencies of coverage in the current health care system have been the strongest contributor to these inequities. However, with the expansion of coverage for most Americans under the recent Patient Protection and Affordable Care Act,[6] the relative importance of disparities due to insufficient coverage should decline and the relative importance of professionalism as a positive contributor to reducing inequity will increase.

APPLICATION OF PROFESSIONALISM TO QUALITY IMPROVEMENT

Patient-centered care is at the heart of medical professionalism. All of the definitions of medical professionalism (Table) are built around patient-centered care, and several of the American Academy of Neurology Ethics, Law, and Humanities Committee attributes of professionalism involve patient-centered care. A specific proposal that is part of the recently passed health reform legislation is the patient-centered medical home, a proposal for restructuring care processes and health care provider payments to make care more patient-centered.[28] In the 1980s, it was noted that neurologists were the primary care provider for up to 20% of their patients.[29] A proposal made in 1995 stated that neurologists should provide both primary and specialty care to patients with chronic neurological conditions.[30] At the time, this was called *principal care*. Neurologists should be included in the national effort to develop the patient-centered medical home so that it will allow patients with chronic neurological conditions to be managed by health care providers who are knowledgeable about those conditions and are compensated in a way that allows for the desired patient-centeredness of care. While there are no systematic studies of this approach, available evidence suggests that this would improve the satisfaction of all parties involved. One example of potential increased funding for coordination of care relates to community-based care of patients with chronic pain. There is at present a dearth of specialists trained and willing to care for these patients in most communities. Yet, primary care physicians are clamoring for assistance, and novel means of consultation through electronic and telephonic methods will likely evolve.

Many neurologists are frustrated by having scheduled patients who do not keep their scheduled appointments, seeing patients who are not appropriately referred, seeing patients who are referred without essential information, and having to overbook urgent patients, sometimes leading to long in-office waits for scheduled patients. This leaves them feeling that they have little control over the timeliness of their care. As professionals, neurologists should take ownership of the problem; as potential health systems engineers, they should develop solutions. One approach promoted by the Institute for Healthcare Improvement[31] and implemented in some integrated health care delivery systems[32] including the Department of Veterans Affairs Health Care System[33] is the use of service agreements. Service agreements are agreements made between referring primary care providers and specialists. The specialist agrees to see referrals within a stated time frame if the primary care provider follows specified guidelines regarding which patients should be referred and what evaluations should be completed by the primary care provider before the patient is referred. The primary care provider gains by having specified guidelines for evaluation and referral, while the specialist gains by seeing more appropriate referrals with the needed information. The patient benefits from more timely and efficient evaluation. Such agreements have been implemented widely in the Department of Veterans Affairs Health Care System and are beginning to be used in some integrated health care delivery systems. While systematic studies demonstrating reduced waiting times have not been published, anecdotal reports suggest that these agreements have reduced waiting times and improved patient and health care provider satisfaction.

Many neurologists believe that equity of care is determined by fi-

©2010 American Medical Association. All rights reserved.
Downloaded From: https://jamanetwork.com/ by a CDC – Center For Disease Control User on 04/18/2019

nancial and other issues that are out of the individual practitioner's control. As professionals, neurologists have a critical role in assuring the equity of care by advocating for their patients. A number of studies cited earlier suggest that access to new therapies such as thrombolytic therapy is not equitable.[19,20] Neurologists are in a position to understand the care processes involved and to advocate on behalf of their patients. Other evidence suggests that persons with disabilities have reduced access to preventive services.[27] Neurologists, as professionals, must assure that the care their disabled patients receive is comparable to that received by nondisabled patients. Neurology professionals must use their position as health care systems leaders to assure that care is equitable.

BARRIERS

Practicing neurologists face a number of barriers in trying to improve the patient-centeredness, timeliness, and equity of care. Whether practicing in solo practice or small groups, as is true for more than 50% of neurologists,[34] or in larger multispecialty groups or integrated delivery systems, all neurologists have to address financial, operational, and human resource issues that frequently take precedence over quality improvement issues. These pressures are likely to worsen over the next 2 decades as current workforce projections show little increase in numbers of neurologists but a demand that is likely to significantly increase owing to the aging of the baby boom generation. This is likely to be most difficult in rural areas.[35] Therefore, procedures and policies must be developed for every practice to directly address quality improvement goals. For example, office procedures can be reviewed to identify ways of improving the timeliness and patient-centeredness of care. These efforts could be undertaken as part of the soon-to-be-required quality improvement projects in the maintenance of certification program of the American Board of Psychiatry and Neurology. In larger organizations, neurologists may need to advocate internally for quality improvement as experience in large integrated health care delivery systems has shown that to be effective, quality improvement must be integrated into overall organizational goals.[36]

OPPORTUNITIES

There are a number of ways that neurologists, both as individual practitioners and as members of the profession, can contribute to improvements in the timeliness, patient-centeredness, and equity of care. In their own practices, they can implement policies designed to improve these aspects of care quality. Most practices can address language issues by using telephone translation services. Some may be able to use electronic medical records to improve visit efficiency by providing visit templates and improving access to old records, increase the speed and accuracy of prescribing, enhance communications with patients by providing them with printed visit summaries at the time of check-out, and improve communication with other health care providers through improved access to medical records. Some electronic medical records may also facilitate office audits of issues such as in-office waiting times or waiting time for follow-up of test results. In some practices, it may be possible to use patient questionnaires targeting the patient-centeredness, equity, and timeliness of care to identify areas for improvement. Larger practice groups may be able improve the patient-centeredness of care by providing information and education programs targeting specific subpopulations of patients (eg, those with migraine, multiple sclerosis, or epilepsy) that share specific issues. Traditional quality improvement vehicles such as mortality and morbidity conferences can be updated to more broadly address quality improvement goals. For example, a recent report outlines the use of a health care improvement matrix tool in such a program.[37] Hospital-affiliated neurologists can involve themselves in other local quality improvement efforts such as quality improvement teams. All neurologists can participate in organizations including state medical societies or national specialty organizations to improve all aspects of care quality through changes in health care legislation and regulation. As professionals, neurologists must take a leadership role in the health care system and advocate for improvements in care quality for their patients.

CONCLUSIONS

The take-home message for neurologists from these approaches to improvements in timeliness, patient-centeredness, and equity of care may be less about the specifics of their solutions and more about the role of the neurologist in managing the systems and processes of care. In each case, to understand the problem, it is necessary to take the view of the patient. The role of the physician, including the neurologist, remains firmly tied to serving as the patient's advocate in a complex environment. As health care is increasingly the product of a system of care, patients look to physicians to serve as their advocates. This means that physicians must not only advocate for each patient as he or she navigates the health care system but also serve as a patient advocate more generally in the redesign of systems of health care delivery.

Accepted for Publication: June 9, 2010.
Correspondence: Christopher T. Bever Jr, MD, MBA, Department of Neurology, University of Maryland School of Medicine, 110 S Paca St, Third Floor, Baltimore, MD 21201 (cbever@umaryland.edu).
Author Contributions: *Study concept and design:* Bever, Franklin, Kaufman, and Esper. *Acquisition of data:* Bever. *Analysis and interpretation of data:* Bever, Franklin, and Esper. *Drafting of the manuscript:* Bever, Franklin, and Esper. *Critical revision of the manuscript for important intellectual content:* Bever, Kaufman, and Esper. *Administrative, technical, and material support:* Esper.
Financial Disclosure: None reported.

©2010 American Medical Association. All rights reserved.
Downloaded From: https://jamanetwork.com/ by a CDC – Center For Disease Control User on 04/18/2019

REFERENCES

1. Institute of Medicine. *Crossing the Quality Chasm: A New Health Care System for the 21st Century.* Washington, DC: National Academies Press; 2001.
2. French J, Gronseth G. Lost in a jungle of evidence: we need a compass. *Neurology*. 2008; 71(20):1634-1638.
3. Franklin GM, Budenholzer BR. Implementing evidence-based health policy in Washington State. *N Engl J Med*. 2009;361(18):1722-1725.
4. Ginsburg PB. Controlling health care costs. *N Engl J Med*. 2004;351(16):1591-1593.
5. American Board of Internal Medicine. *Project Professionalism, Professionalism in Medicine: Issues and Opportunities in the Educational Environment*. Philadelphia, PA: American Board of Internal Medicine; 1995:1-46.
6. Patient Protection and Affordable Care Act, HR 3590. Pub L No. 111-148. March 23, 2010.
7. Medical Objectives Writing Group. Learning objectives for medical student education: guidelines for medical schools: report I of the Medical School Objectives Project. *Acad Med*. 1999; 74(1):13-18.
8. Medical Professionalism Project. Medical professionalism in the new millennium: a physicians' charter. *Lancet*. 2002;359(9305):520-522.
9. American Academy of Neurology Ethics, Law, and Humanities Committee. Humanistic dimensions of professionalism in the practice of neurology. *Neurology*. 2001;56(10):1261-1263.
10. Berwick DM. What "patient-centered" should mean: confessions of an extremist [published online May 19, 2009]. *Health Aff (Millwood)*. 2009;28(4): w555-w565. doi:10.1377/hlthaff.28.4.w555.
11. Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med*. 2005;20(10):953-957.
12. Grosset KA, Grosset DG. Patient-perceived involvement and satisfaction in Parkinson's disease: effect on therapy decisions and quality of life. *Mov Disord*. 2005;20(5):616-619.
13. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract*. 2000;49(9):796-804.
14. Yu RF, San Jose MC, Manzanilla BM, Oris MY, Gan R. Sources and reasons for delays in the care of acute stroke patients. *J Neurol Sci*. 2002;199 (1-2):49-54.
15. Morris DL, Rosamond W, Madden K, Schultz C, Hamilton S. Prehospital and emergency department delays after acute stroke: the Genentech Stroke Presentation Survey. *Stroke*. 2000;31 (11):2585-2590.
16. Lindsberg PJ, Häppölä O, Kallela M, Valanne L, Kuisma M, Kaste M. Door to thrombolysis: ER reorganization and reduced delays to acute stroke treatment. *Neurology*. 2006;67(2):334-336.
17. Daniell WE, Fulton-Kehoe D, Chiou LA, Franklin GM. Work-related carpal tunnel syndrome in Washington State workers' compensation: temporal trends, clinical practices, and disability. *Am J Ind Med*. 2005; 48(4):259-269.
18. Agency for Healthcare Research and Quality. National Healthcare Disparities Report, 2003. http://www.ahrq.gov/QUAL/nhdr03/nhdrsum03.htm. Accessed October 22, 2009.
19. Vickrey BG, Shapiro MF. Disparities research in neurology: an urgent need. *Nat Rev Neurol*. 2009; 5(4):184-185.
20. Menon SC, Pandey DK, Morgenstern LB. Critical factors determining access to acute stroke care. *Neurology*. 1998;51(2):427-432.
21. Jacobs BS, Birbeck G, Mullard AJ, et al. Quality of hospital care in African American and white patients with ischemic stroke and TIA. *Neurology*. 2006;66(6):809-814.
22. Magner D, Mirocha J, Gewertz BL. Regional variation in the utilization of carotid endarterectomy. *J Vasc Surg*. 2009;49(4):893-901.
23. Lechtzin N, Wiener CM, Clawson L, et al; ALS CARE Study Group. Use of noninvasive ventilation in patients with amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Other Motor Neuron Disord*. 2004;5(1):9-15.
24. Marrie RA, Cutter G, Tyry T, Vollmer T, Campagnolo D. Disparities in the management of multiple sclerosis–related bladder symptoms. *Neurology*. 2007;68(23):1971-1978.
25. Cheng EM, Siderowf AD, Swarztrauber K, et al. Disparities of care in veterans with Parkinson's disease. *Parkinsonism Relat Disord*. 2008;14 (1):8-14.
26. Begley CE, Basu R, Reynolds T, et al. Sociodemographic disparities in epilepsy care: results from the Houston/New York City health care use and outcomes study. *Epilepsia*. 2009;50(5):1040-1050.
27. Havercamp SM, Scandlin D, Roth M. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep*. 2004;119(4):418-426.
28. Rittenhouse DR, Shortell SM. The patient-centered medical home: will it stand the test of health reform? *JAMA*. 2009;301(19):2038-2040.
29. Franklin GM, Ringel SP, Jones M, Baron A. A prospective study of principal care among Colorado neurologists. *Neurology*. 1990;40(4):701-704.
30. Kurtzke JF, Houff SA. A primary care plan for neurology. *Neurology*. 1995;45(6):1052-1061.
31. Institute for Healthcare Improvement. Create and implement service agreements between primary care and specialty care and with diagnostic entities. http://www.ihi.org/IHI/Topics/OfficePractices/Access/Changes/IndividualChanges/CreateandImplementServiceAgreementsBetweenPrimaryCareandSpecialtyCareandwithDiagnosticEntities.htm. Accessed October 22, 2009.
32. Federal Expert Work Group on Pediatric Subspecialty Capacity, Maternal and Child Health Policy Research Center. Promising approaches for strengthening the interface between primary and specialty pediatric care. http://www.mchpolicy.org/documents/InterfacePromisingPracticesReport.pdf. Accessed October 22, 2009.
33. Improving patient access to specialty care through implementation of service agreements. *Mag Ambul Prim Care*. December 2003:5-6.
34. Freeman WD, Vatz KA. The future of neurology. *Neurol Clin*. 2010;28(2):537-561.
35. Goldstein LB, Bonito AJ, Matchar DB, et al. US national survey of physician practices for the secondary and tertiary prevention of ischemic stroke: design, service availability, and common practices. *Stroke*. 1995;26(9):1607-1615.
36. Sanfilippo F, Bendapudi N, Rucci A, Schlesinger L. Strong leadership and teamwork drive culture and performance change: Ohio State University Medical Center 2000-2006. *Acad Med*. 2008;83(9): 845-854.
37. Bingham JW, Quinn DC, Richardson MG, Miles PV, Gabbe SG. Using a healthcare matrix to assess patient care in terms of aims for improvement and core competencies. *Jt Comm J Qual Patient Saf*. 2005;31(2):98-105.

Announcement

Sign Up for Alerts—It's Free! *Archives of Neurology* offers the ability to automatically receive the table of contents of *Archives* when it is published online. This also allows you to link to individual articles and view the abstract. It makes keeping up-to-date even easier! Go to http://pubs.ama-assn.org/misc/alerts.dtl to sign up for this free service.

©2010 American Medical Association. All rights reserved.

Downloaded From: https://jamanetwork.com/ by a CDC – Center For Disease Control User on 04/18/2019