Access to the Medical Record for Patients and Involved Providers: Transparency Through Electronic Tools

Physicians’ notes are one of the oldest tools in medicine and have evolved into today’s electronic medical record. As we move toward greater transparency in health care, one emerging concept is that sharing information among patients, caregivers, and involved clinicians can improve efficiency, decrease redundancy, and decrease cost (1). The concept of improving health care delivery by sharing the medical record with the patient is not new (2). The Obama administration highlighted the importance of improved information technology by directing incentive payments totaling $27 billion over 10 years to encourage the meaningful use of electronic health records. One of the meaningful use objectives is to provide patients with an electronic copy of their health information (3). The electronic medical record and Internet technology, using patient and involved provider portals, provide new opportunities to engage our patients and other providers in care.

In this issue, 2 articles address the primary care physician providing others with access to a patient’s electronic health information. Walker and colleagues (4) surveyed patients and their primary care providers about their attitudes before initiation of a voluntary program of sharing the primary care physician’s notes with patients. Zulman and colleagues (5) solicited Veterans Affairs (VA) patients’ views about sharing the contents of their personal health record with their caregivers and other involved providers outside the VA system. Both studies carefully test the waters of sharing medical records. The results are hardly surprising.

The 37,856 patients in Walker and coworkers’ study came from primary care practices in 3 locations throughout the United States. Patients were uniformly enthusiastic about the opportunity to see what their doctors had written about their visits and that interest did not differ with demographic characteristics or underlying medical conditions. Many patients also indicated an interest in sharing their primary care physician’s notes with other caregivers and providers. However, the primary care physicians were less enthusiastic. Those who agreed to participate in the program believed that communication and satisfaction would be improved, whereas those who declined feared adverse consequences, including patient confusion. Many were concerned that the open notes would lead to longer visits and more demands on their time between visits.

Zulman and colleagues studied 18,471 patients throughout the VA system and found that 4 out of 5 were interested in having their health record shared with caregivers and clinicians outside the VA system, but they differed in what elements of the record they were willing to share. Of note, the VA proposal involved sharing labora-

tory results, secure communication, and medication lists in addition to encounter notes.

It is worth noting that both surveys were done in advance of implementing any actual record sharing. Why such caution? Privacy concerns and compliance with the Health Insurance Portability and Accountability Act of 1996 seemed to surface in all such discussions. However, patients have the right to view their own medical record and should be allowed to control who else sees it. Current electronic technology makes it possible not only to enable patients to view their own record but also to grant permission for others to see it, be it a family member, a caregiver, or an involved provider in another location. Such sharing of information could greatly improve communication, engage patients in their care, and help them formulate questions in advance of a visit on the basis of prior notes and test results.

At the University of Texas M.D. Anderson Cancer Center, we developed and implemented access to our electronic medical record for patients and their referring physicians by using our electronic medical record and a secure Web-based portal. Despite physician concerns that the system would increase workload and create unnecessary anxiety for patients, few have voiced complaints since the system went live in May 2009. Despite little promotion of the site to patients, to date more than 40,000 individuals have viewed their records over 605,000 times. In that same period, more than 1300 referring physicians accessed the records of the patients they referred to us over 28,000 times. Currently, 84% of our active patients have obtained access to their electronic records. As a result, they are more informed about their care plan and diagnostic results and ask smarter, more focused questions. There have been no adverse consequences and generally positive feedback from patients and physicians. Although physicians occasionally complain about the time it takes to explain something they wrote, feedback from both patients and physicians has generally been positive. Patients have become avid readers of their notes—their 2 most common requests are for a correction of something recorded incorrectly and for a simple method of translating medical terminology within the record. Our referring physicians are happy with the tool, and we are planning to cease mailing records to referring physicians.

Informed by the results of these 2 studies and our experience at M.D. Anderson, where should we be going? We believe that the direction is clear: Technology is a powerful tool that can improve transparency in health care. Electronic health records should be used to engage patients, their caregivers, and others in the health care delivery system. Expanding who uses the records and how they

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use them promises to facilitate communication, decrease redundant testing, and enhance our care delivery in ways we have yet to imagine. However, health care providers must ask and seek answers to critical questions as we move ahead.

How will patients use their record? Will they share it with family members, and other physicians, and others? Will they feel more engaged in their care? Will their age affect how they use the record? Will they use it when they see another health care provider to possibly prevent another blood sample from being drawn or x-ray being taken or simply to help another provider gain an understanding of previous therapy? Will patients transfer their health information into personal or online repositories of health data, such as those created by Microsoft and Dossia (6)? How can we demonstrate the effect of record sharing on quality of care? Could electronic translators and other tools aid patients in understanding their records? Can patients participate in the entry of data into their own records? Will providers’ notes change if they know patients will read them? Might notes evolve such that they help patients better understand their condition and treatment plan?

Any health care organization with an electronic medical record and a secure Internet portal can provide patients and referring physicians with real-time access to medical records from anywhere in the world, opening the door to levels of patient engagement and care coordination not previously possible. Yet, like any major change in our health care delivery system, we must study its impact to continuously improve implementation. As younger generations embrace technology, one of the oldest tools in medicine, the doctor’s note, is in its infancy of reform.

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