Pushing the Envelope of Electronic Patient Portals to Engage Patients in Their Care

Use of electronic health record systems is increasing at a rapid pace, with the percentage of physicians using such systems in their practices growing from 17% in 2008 to 34% in 2011 (1). Financial incentives created by the Health Information and Technology for Economic and Clinical Health Act of 2009 and guided by regulations subsequently developed by the Office of the National Coordinator for Health Information Technology have largely motivated this growth. Stage 1 “meaningful use” criteria included providing patients with an electronic copy of their health information, while proposed stage 2 criteria are broadened to include the ability for patients to view online, download, and transmit information about a hospital admission. This is certainly encouraging greater efforts at creating “patient portals,” although most established portals to date have provided only limited data to patients in the form of laboratory and test results, medication lists, and visit or hospital summaries. Patient access to physicians’ notes has generally not been part of these efforts.

In this issue, Delbanco and colleagues (2) describe the results of a 1-year experiment, OpenNotes, that allowed patients direct access to their primary care providers’ electronic progress notes through patient portals. The study involved providers and patients from 3 centers, and many of the participating patients already were users of online portals linking them to their institution’s medical record system. Providers and patients were surveyed before and after, and provider responses were compared with those of providers who originally declined to participate. Participating providers were much more positive than nonparticipants about the potential for OpenNotes before the experiment, and concerns that participating physicians voiced at the project’s beginning were alleviated by the end. Yet, a substantial proportion reported that OpenNotes did influence the content and character of the documentation. Attitudes of patients who used OpenNotes were largely positive, and most believed that having access to the information provided many benefits, including enhanced understanding, improved medication adherence, and a greater sense of control. Privacy was the biggest concern among patients.

Although patients technically “own” their medical records, processes for obtaining them have been arduous and many patients do not avail themselves routinely of this service. Physicians and other professional staff have therefore traditionally viewed medical records as primarily for their use, as a means of documenting care for future reference and of communicating with other providers, and have not worried much about how that documentation might affect the patient. Given this background, the physicians’ apprehension about the consequences of having their notes electronically accessible to patients is understandable.

But a revolution is occurring in health care documentation with the widespread implementation of electronic medical records, particularly the development of patient portals. Patients, many of whom already have access to some electronic medical information, have become savvy consumers of online health information, and will demand more. The way that we as physicians view the medical record needs to change accordingly.

Still, OpenNotes may not be for everyone—at least not yet. This study is important because it demonstrates the feasibility of this kind of access for selected providers and patients. Few of the patients indicated that the notes were confusing or offensive, and a large percentage of patients at 2 of the sites viewed their notes at least once. However, participants at these sites were already users of their institution’s patient portal. Prior research suggests that this may not be the case in other settings, given that only 30% to 50% of eligible persons sign up and access patient portals, and those who do tend to be more educated and are more likely to be white than a racial-ethnic minority (3–6). Generalizability may also be limited because of the characteristics of the provider participants, who were younger than nonparticipant providers (7). It is likely that this, together with other as-yet-unknown provider characteristics, will predict how successful such efforts will be.

The OpenNotes project identifies a number of issues that should be evaluated to understand the full value of free access to physician notes. What is the effect on provider-to-provider communication if they modify their documentation practices because of concerns about patient reactions? Will this impair the ability of other providers to manage patients appropriately? If OpenNotes is expanded in scope, what is the impact on physician time and documentation? Is OpenNotes most useful in certain patient populations, and can it have a significant impact on patient outcomes and patient attitudes about their care? Does it have the same effect in populations of patients who may not be as engaged in their health care at baseline? Critical components of the experiment included the ability of providers to “block” certain notes from being viewed and to exclude patients with mental illness. Physicians are more likely to accept broad access for patients if they can continue to maintain some kind of control in specific situations.

OpenNotes is a brave effort at pushing the frontier of patient engagement in their health. While an experiment like this raises concerns for many physicians, the strong message from patients is that it makes them better patients. OpenNotes or similar systems will, over time, become the norm, and physicians should embrace the concept while trying to identify the best ways to use it. It is critical that future work identify when these systems may pose risks;
which patients benefit the most from them; and how best to incorporate them into an ever-increasing arsenal of electronic tools aimed at improving patient care, outcomes, and experience.

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