

Doctors are cautious, patients enthusiastic about sharing medical notes

December 19 2011

Patients are overwhelmingly interested in exploring the notes doctors write about them after an office visit, but doctors worry about the impact of such transparency on their patients and on their own workflow, a Beth Israel Deaconess Medical Center (BIDMC) study suggests.

In a study published in the Dec. 20 issue of the [Annals of Internal Medicine](#), patient and doctor attitudes were surveyed extensively prior to the launch of the OpenNotes trial in which [patients](#) at BIDMC, Geisinger Health System of Danville, PA, and Harborview Medical Center in Seattle were offered online access to their doctors' notes written after office visits. Such notes have long been primarily within the doctors' domain, even though patients have the legal right to obtain them.

"[Doctors](#) were divided in many of their expectations, and the issues we highlight have important consequences for both their work life and quality of care," writes lead author Jan Walker, RN, MBA, of BIDMC's Division of General Medicine and Primary Care.

While many of the more than 100 [primary care](#) doctors who volunteered to participate in this experiment predicted possible [health benefits](#) from allowing patients to read their notes, the majority of those who declined participation were doubtful about positive impacts. And among the 173 doctors completing surveys, the majority expressed concerns about confusing or worrying patients with the content. Doctors also anticipated that they would write their notes less candidly and that responding to

patient questions might be exceedingly time-consuming.

In contrast to the doctors surveyed, the nearly 38,000 patients who completed the baseline survey were almost uniformly optimistic about OpenNotes, and few anticipated being confused or worried

"The enthusiasm of patients exceeded our expectations," wrote Walker. "Most of them were overwhelmingly positive about the prospect of reading visit notes, regardless of demographic or health characteristics."

More than 90 percent favored making the notes available. Well over half anticipated improved adherence to their medications, 90 percent expected to feel more in control of their care, and four out of five predicted they would take better care of themselves.

"We know a lot more about our cars than our own bodies," responded one patient. "We leave all of that to the clinicians. I think by having access to our notes, we can take control, and that's important."

In addition, half of patients surveyed reported that they would consider sharing their notes with other people, including other doctors.

"As I help my aging mother with her medical needs, I wish I could see the notes her doctors have made," wrote one patient. "I think it would help me in caring for her."

In an accompanying editorial, Thomas W. Feeley, MD, of the MD Anderson Cancer, and Kenneth I. Shine, MD, of the University of Texas, urged that electronic health records be used to engage participants in all parts of the health care delivery system.

"Expanding who uses the records and how they use them promises to facilitate communication, decrease redundant testing, and enhance our

care delivery in ways we have yet to imagine."

The year-long OpenNotes study period has now ended, and Walker and her colleagues in the three diverse sites are eager to learn how the baseline expectations will play out. They are currently evaluating reports from follow-up surveys completed by participating doctors and patients and analyzing other metrics, such as how often patients reviewed their notes, shared them with others, or corrected errors their doctors may have made.

"They said they wanted the notes. They said they'd use them, but we have no idea if they actually went online and read them," said Walker. "And if they did read them, we don't know yet what impact that had on the patients or the doctors."

"Patients want to look into the doctor's black box, and many doctors are a bit nervous about what they'll find," said Tom Delbanco, MD, senior author and co-principal investigator of OpenNotes. "But I expect that over time everyone will benefit enormously from such transparency."

"While OpenNotes represents a simple change of practice, the effect on the patient-doctor relationship could be profound. The fact that there's such a gap between how most patients and many doctors expect that patients will handle the information contained in these notes hints at just how profound that effect might be," added Steve Downs, Robert Wood Johnson Foundation's Chief Technology and Information Officer.

Provided by Beth Israel Deaconess Medical Center

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