Can Deciphering Doctor's Notes Improve Care?

Lauran Neergaard, AP Medical Writer

WASHINGTON (AP) — Don't be offended if your doctor writes that you're SOB, or that an exam detected BS.

The aim is to help, not insult: A project is beginning to test if patients fare better when given fast electronic access to more of their medical chart — the detailed notes that doctors record about you during and after every visit. You just might have to look up some of the technical jargon, like those abbreviations for "shortness of breath" and "bowel sounds."

Didn't know about those notes? Researchers involved in the "OpenNotes" project say they are surprised at how many patients don't.

"You really have to be a partner with your doctor to do well," says Dr. Tom Delbanco of Harvard and Beth Israel Deaconess Medical Center, who heads the study and thinks better use of those notes will help.

"It's your body. It's your record. It's your illness. You should have ready access to everything about it."

Yes, your clinic may have an electronic records system that lets you log in to make an appointment, check your cholesterol test or review your medications. But Delbanco and nursing colleague Jan Walker have found few include those doctor notes that provide details about a patient's health.

They can stretch two or three pages, as doctors mull alternate diagnoses they may not have mentioned, like a test ordered to rule out cancer.

Or doctors may jot reminders about personal issues that could complicate care — maybe the patient ignores medical advice, or is in denial, or has financial difficulties.

Doctors may detail problems in more blunt terms than they'd used face-to-face.

Hence easier access is debated. Say the doctor carefully avoids the "O'' word while urging you to lose 20 pounds, only to write that "Joe is obese." Will you get mad, or be more likely to follow the advice?

To find out, three large health centers — Beth Israel, the Geisinger Health System in Pennsylvania and Seattle's Harborview Medical Center — are enrolling 115 doctors and up to 25,000 patients in the OpenNotes study.

For a year, participants will get an e-mail after each office visit saying their doctor's note is available through a secure online portal. Researchers will track if patients read it and find errors, and how they use it. Doctors' habits are being tracked, too — if they censor themselves or write more patient-friendly notes.

It's not just for the Web-savvy and well-off. Among the Seattle participants are homeless patients who can log in at such places as the public library.

Harborview's Dr. Joann Elmore sees the potential value: She has a patient who e-mails health questions from remote Alaskan fishing camps where he travels seasonally to find work. But she also wonders if patients with low literacy, especially, can use the notes. After all, they're intended mostly to jog the doctor's memory, communicate with other physicians and justify insurance billing.

Indeed, in Monday's Annals of Internal Medicine, Delbanco and Walker describe doctors' fears of time lost editing their words or calming patients upset at reading of, say, an inconsequential heartbeat irregularity — while patients say they want the information but wonder if they'll misinterpret something. To further check interest, the journal is posting a survey for doctors and the general public alike at http://www.annals.org [1].

By federal law, you can get a copy of everything in your medical chart, visit notes included, by filing a formal request, but it can be difficult. Clinics may take two or three weeks to respond, and Delbanco says copying fees can run as high as 75 cents a page. Seattle's Elmore last week saw a woman who'd succeeded in getting records from just one of four care sites; her office intervened to help get the rest.

Given the hurdles, patients rarely seek copies of their medical records unless they're facing a big illness, says Stephen Downs of the Robert Wood Johnson Foundation, which is funding the $1.4 million OpenNotes study.

With growing use of electronic records making easier access possible, the question becomes whether doctors will write easier-to-understand notes to help engage patients in their care, he says.

"The way I view my relationship with the doctor is, I'm the CEO of me and he works for me," says Ed Leonard, an engineer in Acton, Mass. He'd never seen a doctor's note until a recent visit to Delbanco, but he welcomed the change.

Another patient stopped an error by telling a doctor that her note didn't mention the tests she'd promised to order, Walker says.

And in New Hampshire, where the Dartmouth-Hitchcock Medical Center provides routine electronic access to doctor's notes, Dr. Mary Merkel inadvertently shamed a diabetic into better health. Three months after she wrote that he was "noncompliant," he returned 30 pounds lighter, saying he'd felt bad at her disappointment in him.

"I don't want to hurt my patients' feelings," says Merkel, admitting she'd had a hard

time telling the man how badly he was doing. "Who knew this could be such a powerful tool?"

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