DEBATE: PART I

Benefits from Destroying the Black Box (or Are We Opening Pandora's Box?)

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These days, commentary about bankers, politicians, or school systems is almost invariably accompanied by a call for "increased transparency." And it's not different for us in medicine. Spurred by electronic technologies, black boxes are being torn open right and left, bringing disruptive changes to both doctors and patients. We applaud these changes and argue that attendant benefits will far outweigh risks. And whether you agree or not, it's probably futile to try to interfere with an unstoppable progression.

It doesn't take much effort to recognize the connection between the societal move toward transparency and fundamental changes in medicine. "Open disclosure" is sweeping aside "keep your mouth shut" in strategies addressing medical error. Surveys ask patients to report about their care, and payments to providers will soon reflect their patients' observations. Patients share their assessments of doctors on popular websites. Now, Secretary Sebelius proposes that patients' ready access to their laboratory test results become the law of the land.[1]

We agree with Secretary Sebelius that "information is power" and fully support her proposal to make testing transparent to patients. By now there is ample precedent. Electronic patient portals offer more and more patients secure and direct access to test results; some have existed for more than 10 years, and the world has not collapsed as a result. To be sure, some patients learn bad news before their doctors intervene, but these cases are the rare exception rather than the rule, and embargoes, such as a week-long delay before opening radiology, pathology, CEA, or HIV results, have assuaged most fears among doctors who work in these open data environments. As the proposed rule moves forward, some of these "delaying" techniques should be considered.

Offering patients access to laboratory tests, and indeed offering them entry into more and more of medicine's black box, will advance the health of the nation. Indeed, we propose what is arguably an even more disruptive innovation—offering patients ready access to their doctors' notes. Moreover, we suggest considering open lab results and open visit notes as new medicines: Benefits should outweigh risks for the vast majority of those who use them; both patients and doctors need to learn to use them well; they will likely have both absolute and relative contraindications; and although these interventions are expensive now, once other analogous "formulations" compete with them, and certainly when in time they become "generic," the price will fall sharply.

Doctors are socialized to read critically. A new study appears, and the first impulse is to search for what's wrong with the recommendations rather than what's possibly really good news. So we'll list first some potential downsides from openly sharing lab test results and visit notes:

1. A patient may discover bad news without benefit of the presence and interpretation of his/her doctor.
2. Some patients may besiege doctors with requests for trivial corrections, unimportant questions, e-mails, and phone calls that could bring busy practices to a grinding halt.
3. Doctors may have elements of their practices and recommendations challenged as notes and tests are forwarded to other clinicians (and lawyers?).
4. Doctors' notes may insult, confuse, or frighten patients with speculations about a possible cancer, with terms such as "SOB" and "obese," and with words contemplating alcohol abuse, depression, or borderline personality.
5. Patients may worry about "abnormal" results that the doctor considers inconsequential.
6. Once patients understand what is recorded in notes, some may withhold important information for fear of it being written down.
7. Doctors may water things down so that covering or consulting doctors don't get enough from their colleagues' notes.
8. Patients may accuse doctors of lying or exaggerating about a visit (the breasts unexamined, the five minutes that the doctor claims took half an hour).
9. And overall, depending on the viewer, medical records may lose focus when adding patients and their families to the myriad current users: other doctors, administrators, payers, lawyers, quality measurers, nurses, social workers, other clinicians, and snoops.[2]

So, potential downsides may carry greater or lesser degrees of negative impact. But recall John Stuart Mill's utilitarian plea for a society that seeks the "greatest good for the greatest number." What about positive consequences for both health and disease that might derive from

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such new medicine? Are they not worth the risks?

Supported in part by the Robert Wood Johnson Foundation Pioneer Portfolio, we have undertaken a demonstration of "open notes" to learn more. In a survey of 170 PCPs and 38,000 patients from Boston, rural Pennsylvania, and the Seattle inner city, we sought their expectations about inviting patients to read visit notes online. Consider the following:

1. Eighty percent of the patients predicted they would take better care of themselves, 90% anticipated feeling more in control of their health care, and 90% thought they would understand their health and medical conditions better.[3]
2. With poor adherence to medications persisting as one of medicine's greatest challenges, two out of three patients who were taking medicines in this sample predicted they would take them more appropriately. (Perhaps they were optimistic, but if only 20% found after working with open notes that this was indeed the case, we would have an extraordinary advance in care.)
3. Fewer than 15% anticipated being worried or confused by such notes—in sharp contradistinction to their doctors' gloomy expectations. (Let's not forget how resourceful patients can be when researching things they initially may not understand.)
4. Joined at times by family members or other caregivers following the visit and in the comfort of their homes, patients will have a chance to correct and amplify memories of an encounter, consider the details, examine results and trends, and reflect on next steps.
5. Patient safety may increase. Patients may find important mistakes, including errors in commission or omission. Just a few big ticket triumphs could make up for many "trivial" or inconsequential events.
6. While the doctor/patient relationship at its core remains confidential, it will now be up to patients whether or not it is private. By sharing notes and test results, care may improve as patients involve family, caregivers, and other doctors or nurses more effectively in their care.
7. For every patient who takes more of the doctor's time, another may take less as a consequence of having direct access to his/her own information. Might doctors end up focusing more on those who need them the most? As patients work on their issues more effectively at home, might costs of care diminish?
8. The written word may have more power than fleeting verbal communication. Facing up to the need to address obesity, alcohol abuse, or somatization may be facilitated by observations engraved in the medical record. Such words may hurt initially, but they can also help over time.
9. The doctors' notes may become more honest; misrepresentation may diminish. The important role of teacher can be reinforced as doctors add patients and family members to their audience. Trust, the bedrock of the patient-doctor relationship, may grow or be reaffirmed.

These are just a few of the positive consequences that may derive from inviting patients to view results firsthand and to share in the doctor's thoughts. Over time, we expect that such transparency will lead to convening around a jointly generated medical record that represents a contract—a clear understanding between the patient and doctor of what has happened in the past, where things stand now, and where the two together hope to go in the future. And as we look for better quality metrics, what better than to begin to measure and quantify how well both parties live up to their jointly articulated aspirations?

Our 12 month demonstration study of open notes is coming to an end, and we will soon move beyond describing expectations to publishing the results. Suffice to say that only one of 107 PCPs who volunteered to experiment with open visit notes dropped out during the first year; we have received no death threats (an experience similar to those who more than two years ago led a similar charge at MD Anderson Medical Center),[4] and indeed some doctors and a lot of patients are smiling when we cross their paths. We believe Secretary Sebelius will be pleased with the impact of her proposed rule, and we are confident these types of interventions will bring light into a black box, rather than release the demons Pandora failed to contain.

Reference

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