

Not the Last Word: Seeing Ourselves as Doctors See Us

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In 1786, the Scottish poet Robert Burns asked, “Oh, would some Power give us the gift/ To see ourselves as others see us!” [1]. In 2021, that request was granted, at least in part. A new federal rule [17] mandated that all medical records must be freely available to patients upon request. Patients can now see the very words that doctors have been using to describe them.


The OpenNotes [18] process (as it is called by its advocates) might well foster better and more transparent healthcare.

A note from the Editor-in-Chief: We are pleased to present to readers of Clinical Orthopaedics and Related Research® the next installment of “Not the Last Word.” The goal of this section is to explore timely and controversial issues that affect how orthopaedic surgery is taught, learned, and practiced. We welcome reader feedback on all of our columns and articles; please send your comments to eic@clinorthop.org.

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But there are potential problems, too. For one thing, OpenNotes are likely to be more ambiguous. That’s because physicians will be forced to trade direct but perhaps pejorative terms for less meaningful ones to avoid offending their patients. In time, a consensus might emerge on replacement phrases, and meaning will be restored. The difficulty remains, however, because these new terms—retaining their original derogatory connotations, as they must—will have to be exchanged for still newer ones.

This cycle represents what the linguist Steven Pinker called the “euphemism treadmill” [20]. In the realm of medicine, for example, the terms “idiot,” “imbecile,” and “moron”—all once medical descriptors of mental enfeeblement [10]—have all taken a run on the euphemism treadmill before settling into the vernacular as schoolyard insults.

Beyond the loss of clarity, OpenNotes might cause unnecessary anxiety for our patients. Patients who don’t understand that certain incidental findings are unimportant will be vexed when they read about them. Consider a report of a plain radiograph describing mild arthritis of the knee. The radiologist might describe in passing “subchondral sclerosis.” An orthopaedic surgeon is apt to

quickly gloss over these words; a layperson, by contrast, might persevere on them. A worried patient might even demand a surgical remedy when none is needed or even possible. I can imagine the response: “I get it, Doc, exercises for my arthritis. But what are you going to do about that sclerosis? My dad died of coronary sclerosis!”

If the full potential benefits of OpenNotes are to be achieved, these difficulties must be addressed.

Unfortunately, I don’t have any solutions to the euphemism treadmill and related problems of clarity. It’s human nature to “code shift” and use different words and tones when talking to different audiences. If OpenNotes are to be written in a lingua franca, accessible to both lay and professional audiences, they will be less precise. If OpenNotes are to be written in only bland terms, they will be less informative.

I do have a possible, though partial, solution to the problem of test-result-induced distress: namely, mandating that all incidental findings on imaging studies get labeled as such. This is not as far-fetched as it may seem. What is “incidental” can be defined a priori, if the radiologist were charged with answering a specific clinical question and not simply asked to “tell me what you see.”

Along with Frank Lexa, I proposed that, as a prerequisite for third-party payment, all requests for advanced imaging must be accompanied by a clearly stated clinical question and all

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reports offering interpretations must include a direct answer [3]. Incidental findings, if they are to be included at all, are to be listed separately.

In the case of a lumbar MRI, for example, a physician would not be allowed to order the test saying “rule out disc disease” but rather must state: “My patient has no axial symptoms but has pain radiating to his left big toe. Is there anything present in the spine to explain that?” (This will probably be conveyed in medical shorthand as “rule out L4/L5 nerve root compression.”) In this scenario, if the MRI revealed only a herniated disc at L2, a finding that cannot explain pain radiating to the toe, the official test results would be “Negative.” The L2 disc herniation would be listed separately in a section titled “additional findings.”

Granted, red-flag diagnoses such as tumors must be mentioned in boldface even if detected only incidentally. Also, there are times when the clinical question is “does this patient have cancer?” or when the radiologist can offer only a differential diagnosis (with some scary-sounding elements). Thus, not all anxiety will be averted. Still, in general, a requirement that radiology reports focus on a specific clinical question can prevent patients from overreading.

Overreading medical records is medically harmful. In his now-classic 1994 essay, “The Last Well Person,” Clifton Meador wrote: “The demands of the public for definitive wellness ... combined with clinicians whose tools are powerful enough to find very small lesions, is a setup for diagnostic excess. If the behavior of doctors and the public continues unabated, eventually every well person will be labeled sick” [15].

The OpenNotes process not only fails to abate this process, it abets it. Only with explicit countermeasures to

offset its problems can a program allowing patients to see themselves as doctors see them be the “gift” that Burns and the OpenNotes community imagine it to be.

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A few decades before Scottish romantic poet Rabbie Burns penned the verse Dr. Bernstein quotes in his column, French enlightenment philosopher Voltaire published his masterpiece *Candide*. The satire challenged the resigned, laissez-faire optimism voiced by *Candide*’s tutor, Dr. Pangloss. No matter how dire or imperfect the lead character *Candide* found the world to be, his mentor, Dr. Pangloss, advised him that the imperfections were justified since, “All is for the best” in “the best of all possible worlds” [24]

It would be unfair to liken Dr. Bernstein’s opinions to those of Dr. Pangloss. However, it is also important to challenge the unquestioned default assumption that “closed notes” are for the best [4]. One study [14] found that patients misremember around half of what a doctor says during an appointment. In contrast, with online access, patients report enhanced understanding and recall about their treatment plan [25], including increased medication adherence [3]. Patients also spot documentation errors [6] and say access is important for trusting clinicians [2].

Dr. Bernstein worries patients will become anxious after reading their documentation. Again, patient surveys challenge conventional clinician wisdom. In fact, patients who are denied

access to test results that are in their electronic records often experience medically unwitnessed but real anxiety. One study found “scanxiety”—the distress experienced while waiting for test and scan results—only dissipates when patients obtain their results [7].

And patient confusion turns out to be pretty uncommon, anyway. A study I did with my colleagues at Harvard found that clinicians don’t give their patients enough credit. They understand most of what they read, and withholding it raises serious ethical concerns [5]. In the largest survey looking into notes that are visible to patients, of more than 22,000 outpatients, Walker et al. [25] found only a small minority—3% and 5%—of patients reported being very confused or more anxious by what they read. Salmi et al. [22] conducted a secondary analysis of that study and found a disconnect between oncology clinicians and their patients. The study found that only 4% (n = 131) of patients with oncologic conditions reported finding their notes confusing, compared with 36% (n = 44) of oncology clinicians who believed patients would find the notes “more confusing than helpful.”

Further research is needed to explore whether access leads to objective documentation changes [6]. In a recent study, most primary care physician respondents described modifying language such as “non-compliant” or “patient denies” [9]. Pinker’s euphemism treadmill described by Dr. Bernstein in his column needs the traction of taboo phrases and concepts. Some edits are likely to be both positive and justifiable, overturning long-embedded medical vernacular that is unnecessarily authoritative and paternalistic in tone.

We need to determine whether greater access leads to strengthened patient engagement in their care. It may be that some medical terminology

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becomes less taboo, facilitating deeper, more meaningful conversations between patients and doctors. And yet, some changes might diminish documentation quality, as Dr. Bernstein rightly notes. In a recent survey, 22% (n = 168) of doctors across medical specialties believed their notes were less valuable after patient access [9]. This challenge must be confronted.

Voltaire concludes *Candide* by rejecting Dr. Pangloss' optimistic defense of the status quo, advocating a deeply practical precept: "We must cultivate our garden." Similarly, with the evolving functionality of the electronic health record, students and clinicians will need guidance on how to write and talk about their documentation, which patients can now read, including preserving the accuracy of documentation when confronted with challenging ethical dilemmas including the potential to cause offense. Fortunately, a new curriculum, with materials freely available to all, is being designed by a team of clinicians, patients, educators, and researchers at OpenNotes, a research unit at Beth Israel/Harvard that investigates patient access to their clinical notes online [19].

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Notes in the electronic medical record that are visible to patients, or even immediate online access to full medical records as we have in the Nordic countries, aim to engage and inform patients and increase the transparency and democratization of healthcare. But there appears to come a point

when clinicians experience patients as "too engaged" or "too informed," as described by Rosamund Snow PhD and colleagues in the paper "What happens when patients know more than their doctor?" [23]; patients ask more questions than clinicians might prefer, and they may demand the explanations for and the rationales behind the treatments clinicians are proposing.

In his column, Dr. Bernstein described many of the same concerns expressed by healthcare professionals in Sweden when patients were first offered online access to their records in 2012 [13]: Clinicians won't be able to write everything. Patients will misunderstand us. This is our working tool [12].

Personally, and based on the research into the topic, I believe healthcare providers tend to underestimate patients. In a 2016 Swedish survey study of more than 2500 patients [16], 93% of the respondents reported partly or fully agreeing with the statement, "I understand most of the content of my medical record."

"If we can manage to have all of these cancer diseases and to live with it, then we can handle reading about it." This is a quote from a Swedish patient with cancer who researchers interviewed about immediate online access to electronic health records, including but not limited to notes in the electronic medical record that are visible to patients [21]. In the same study, another patient said, "Accessing test results, it is a tremendous difference, and it really means a lot to me ... It's so difficult to wait, whether it is good news or bad news, it's very good to know." Another patient from the study said: "I think that the information that you have been diagnosed with cancer is worrying no matter how you get it... I think that we should be free to choose how we get

access to that information" [21]. In addition, there is a growing body of evidence indicating the benefits patients experience from reading their records; patients who read their notes report understanding their care plans better [25], feeling more in control of their care [16, 25, 26], doing a better job taking their medications and improved self-care [8, 26], and improved communication with and trust in their clinicians [8, 16, 26].

Clinicians may worry about how to best phrase the notes they write, knowing that patients may read them. I believe that there's likely a need for more systematic education to ensure notes in the electronic medical record that are visible to patients can reach their full potential. Avoiding stigmatizing or offensive language is paramount. Clinicians may argue that they are changing euphemisms, not offensive language, but I prefer to see it as an important cultural change in medicine that should be embraced and welcomed, where patients are treated with respect, even in the written record.

This brings me to the concept of "epistemic injustice," coined by philosopher Miranda Fricker [11]. Epistemic injustice points to a specific kind of injustice done to someone in their capacity as a knower, or as a contributor to knowledge [5]. When patients are described as emotional or incapable of reading their notes without worrying or misunderstanding, it creates a resistance to giving them access to information and knowledge that may be essential for their health and well-being. I think about what Charlotte Blease PhD wrote in her article on notes in the electronic medical record that are visible to patients: "Closed notes are an inherited structure in healthcare, but this doesn't make them right" [4].

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