

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Whom Should We Regard as a Legitimate Stakeholder in the Accuracy of Information in a Patient's EHR?

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Abstract

This commentary on a case canvasses federal and some organizational rules applicable to health record keeping and considers these in light of “open notes.” Accuracy of information in health records, accountability for remediating inaccuracies, and ownership are considered as key areas of ethics investigation.

Case

BG is a patient recently discharged from University Hospital. BG shares access to their online chart with their spouse, MM, who is reviewing information in BG's chart as they coordinate review of their insurance company's explanation of benefits documents and bills from University Hospital. MM is distressed to see how BG is described in the online chart and is outraged by some references entered by Dr C and Dr T, in particular, describing BG's physical appearance, clinical presentation, behavioral symptoms, and experiences. MM worries that some of the words used to describe BG could prompt a future clinician who reads those words to be negatively biased against BG in a possible future clinical encounter. MM also notices inconsistencies in what is documented in Dr C's notes about procedures performed by Dr T, for which they and their insurer have been billed.

MM calls University Hospital's patient relations number to report that “information recorded in BG's chart is factually inaccurate and offensive. The chart notes need to be changed so the right claims can be resubmitted to our insurance and so that anyone else who reviews these notes will know what really happened to BG.”

How should University Hospital, Dr C, and Dr T respond?

Commentary

In 2021, the final rule implementing certain provisions of the 21st Century Cures Act required that clinical notes (commonly referred to as “open notes”) be available electronically on request and free of charge to patients, in a timely manner, with limited exceptions.¹ The provisions were enacted to support information transparency and to improve care.¹ Naturally, this new transparency raises a host of ethical questions as to

what should be included in notes intended to serve many purposes, including care, communication, and payment.² This case raises ethical questions related to information transparency, patient autonomy, professional autonomy and integrity, nonmaleficence, veracity, and fidelity.

Influence of Open Notes

The idea of sharing clinical notes with patients is often met with concern from clinicians. Physicians have reported fearing that open notes would increase their work burden,^{3,4} thereby contributing to already-prevalent clinician burnout.^{5,6} Physicians have also reported worrying that open notes would harm patients who would either not understand or be anxious about what was written, requiring them to limit the content of their notes or not use language that could be perceived as patient criticism to avoid upsetting their patients.^{3,4} Most physicians in one study reported that none of these concerns had materialized.⁴ However, research suggests that patients want access to their health record and that they benefit from seeing it, including by being more proactive about and feeling more in control of their care.^{3,7,8,9} Studies suggest that this transformation to more transparent health care remains remarkably quiet.^{4,7}

Of course, with any change, there can be adverse effects. The practice of open notes is like prescribing medicine. It has benefits for most and side effects for a few, as evidenced by one large survey, which found that the majority of patients reported open notes being important for their health care while only a small percentage reported being confused or worried after reading their notes.⁷ While the practice of note sharing confers benefits to patients, this transparency can raise questions about notes' ownership.

Health Record Ownership

With the American Hospital Association's adoption of the Patient Bill of Rights in 1973,¹⁰ patients' right to access to their health record was established. However, access to that record was generally made so onerous by health care organizations that few patients ever saw their record. As mentioned, the Cures Act required patients' **timely electronic access** to clinicians' notes and test results. With this shift, patients might believe that they "own" the record, as access to their record helps them become engaged in their care and report documentation errors.¹¹ And yet, except for patients living in New Hampshire,¹² they do not; ownership of the information lies with the clinician or organization. These entities have documentation requirements and custodial obligations, many of which can be negotiated with patients, but some of which cannot. Yet patients have a clear stake in what is written in the record. How clinicians balance patient autonomy and privacy interests with their professional responsibilities without tipping into paternalism remains tricky. For instance, if either clinician in the case believed BG was psychotic based upon observations, they would be obligated to write that in the record. However, if BG relayed sensitive information, such as a childhood trauma that was not pertinent to the current clinical situation, then how or whether that information was documented could be negotiated with BG. Without BG's input, a note that states that the patient is "dealing with difficult childhood issues" without details might satisfy professional documentation requirements while being respectful of BG's privacy and autonomy.

In the given example, MM wants her husband's chart changed. This request could devolve into "undue" autonomy if it compromises the clinician's professional obligations. Once a clinical note has been signed by the clinician, it becomes a legal document. Altering a health record is usually not legally permissible,¹³ especially if it

could be viewed as part of an effort to “cover up” an error and shield clinicians or health care organizations from liability. There are rare exceptions,¹³ such as when a clinical note is entered in the wrong patient’s chart. However, most health care record platforms do allow clinicians to make an “addendum”¹⁴ to their signed clinical note. In our case, it should be possible for the clinician to add an addendum to clarify the note or rectify an error or to ensure that MM’s or BG’s perspective is heard.

Differing Perspectives and Documentation Requirements

Patients greatly appreciate having their perspective included in the record, even when it differs from the clinician’s.¹⁵ A common example is when a patient does not believe they are psychotic or delusional, but the clinician does, based upon their professional observations. Clinicians are obligated to **document their professional observations**; however, they can also add the patient’s perspective to the note. Our experience and research¹⁶ suggest that when patients experience clinicians as respectful and inclusive of their perspective, they are generally accepting of the record.

We do not know if the descriptions of BG’s “physical appearance, clinical presentation, behavioral symptoms, and experiences” are accurate from the clinician’s perspective. We can presume that the descriptions are experienced as pejorative, and research suggests that pejorative or biased language in a note can affect the perception of a clinician who reads it.¹⁷ As a corollary example, research has shown how upsetting it is when patients see offensive descriptions, such as *obesity*, in their record.¹⁸ It is hard to imagine any clinician using the term *morbid obesity* in a visit, yet health insurers require this wording for a diagnosis to justify billing.¹⁹ When the language is explained to patients as an artifact of billing, some might be mollified. Yet it does not take away their concern that it will prejudice their care. In the interests of nonmaleficence, we suggest that clinicians shift to using—and that insurers accept—body mass index, weight, or other language to satisfy billing requirements. Most importantly, clinicians should generally not write something that will surprise the patient.¹⁸ “Write what you say and say what you write” is the mantra for these situations.^{20,21,22}

Patients have a right to accountability, including an explanation—in this case, of the language describing BG in clinical notes. It will be important for the physicians and the patient relations department to meet with MM. They should acknowledge that MM’s concerns are well-founded, even if the descriptions of BG’s appearance, behavior, and clinical presentation are accurate. In one hospital, over 25 years ago it became policy that all bioethics consultation notes would be shared with the patient and any involved family member or friend.^{23,24,25} This practice is still considered controversial, and yet the sharing of the record—including, at times, drafts of the consult note—generally bridged any divide and allowed for more partnerships at that hospital.

Inaccuracies

Errors in medical records are common. One large survey has shown that roughly 20% of patients found material errors in their health record, with almost half of these patients perceiving the errors as serious.¹¹ These errors range from those that can be easily corrected to documentation that could potentially constitute fraud. We also know that clinicians frequently use the copy and paste functions of the electronic record to help reduce their work burden, which can perpetuate errors.²⁶

In any bioethics consultation, it is crucial to first ascertain all the facts, including any disagreement about them, as there are always differing perspectives. Factually, we

know that BG, the patient, underwent a procedure while hospitalized. Thus, it is likely that this procedure occurred on a medical or surgical service. There is a health care insurance company involved with benefits and billing. We know that MM, the patient's spouse, is upset by several features of BG's record. We do not know BG's reaction and whether MM is acting as BG's health care proxy or simply playing an advocacy role. It appears that trust has broken down between MM and the team. This distrust might extend to the hospital's patient relations staff. Lastly, MM fears that BG's written record will prejudice future clinicians.

Physicians and the hospital are fiduciaries who owe BG and BG's family a duty of care to do their best for them. Whether the "inaccuracies" in BG's chart noticed by MM are differences in perception, mistakes, errors in care, or evidence of fraud or malpractice, BG and MM are owed explanations and accountability. Accountability includes disclosure to BG and MM of what the hospital is doing to ensure that inaccuracies in documentation do not occur on the charts of any future patient(s). It would thus be preferable for the hospital's patient relations staff to discuss with MM and BG how well the inaccuracies were addressed rather than ignore their concerns. The essential principle in ethics is respect for persons. Transparency in documentation is part of changing the dynamic so that patients are better able to trust that clinicians have a stake in their best interests.

Summary

Clinicians write notes to satisfy a variety of users, including cross-covering clinicians, health insurance companies—and now, patients and families. Patients and families can certainly contribute to, influence, and improve this documentation, especially when they are viewed as partners. Patients should not restrict or change what clinicians write when documentation is fulfilling professional obligations, except when it is in a "negotiable" area of care. Patients have a right of access to, accountability for, and explanations of their record and care, while also offering an additional set of eyes to catch errors and mistakes and thus improve safety. Furthermore, transparent medical records can enhance patients' trust in clinicians and health care organizations and lead to their greater engagement in care.²⁷

Clinicians should write their clinical note as if the patient is sitting with them and reading it. Avoiding words that could convey bias or judgment, ensuring that physical descriptions are objective (eg, BMI), and including empowering and encouraging language could help avoid future issues such as those raised by MM.⁷ The mantra "Write what you say and say what you write" not only comports with principles of beneficence and nonmaleficence, but also can lead to more trusting, engaged, and productive care.

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Editor's Note

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