Partners in Narrative: Empowering Patient–Physician Partnerships in the Electronic Health Record

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Abstract
Amidst the chorus of valid laments about the electronic health record (EHR) are voices calling our attention to its potential to enhance transmission of information, patient communication, and decision-making. Herein, we propose ideas which, in addition, may enhance the potential of physicians and patients to become better at storytelling through the EHR. Clinicians can partner with patients to create meaningful, personalized narratives which restore inclusivity and patient agency to the EHR.

Keywords
clinician–patient relationship, culture/diversity, patient engagement, patient perspectives/narratives, social media, technology

Since its inception, the electronic health record (EHR) has engendered thoughtful expressions of concern about its depersonalizing impacts. Computer-based tasks, for instance, negatively impact how physicians take histories and process patients’ narratives. However, amidst the chorus of valid laments are voices calling attention to the EHR’s potential to enhance transmission of information, patient communication, and decision-making (1-3). If the EHR can make physicians better at filtering information, communicating, and diagnosing, why not also repurpose the EHR to help physicians and patients improve clinical storytelling? The EHR’s arrival has destabilized traditional care paradigms; this disruption should be an impetus to critically examine the lack of inclusivity and patient agency in how patients’ stories are told and, in so doing, shift the paradigm of narrative power in patient–physician relationships.

Reintroducing the Patient into the Patient History

How can physicians partner with patients and EHRs to create meaningful, personalized narratives? EHR-based innovations already allow patients greater access to medical records. Screen sharing in exam rooms is a simple, low-cost way to encourage clinician–patient partnership in the EHR. Patients can now access much of their health information via patient portals. Platforms such as OpenNotes go a step further, allowing patients to review their physician’s progress notes; one study found that most patients with access to written narratives perceived more control over their care. Other models, such as the forthcoming OurNotes, use the EHR to actively involve patients in record co-creation with their physicians (4).

A History of Health, Not Just a History of Present Illness

Strengthening patient voices in the EHR is an important step in the right direction. However, these processes are still conducted largely within the confines of the traditional history and physical documentation format. The result is a depiction of a person which is not in keeping with the modern way they would choose to represent themselves. In life outside the medical chart, people are unlikely to introduce themselves with their age, race, and gender. Imagine starting a conversation with, “Hi, I’m a 34-year-old South Asian female.” Few would say that those words adequately encapsulate who they are and what is most important to them. Why, then, do

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all patient stories begin that way? Patients, too, have lives outside the medical chart, identities that exist outside of their EHR incarnations. Communicating within this traditional template, even when shared with patients, may still dehumanize them, and feel dehumanizing to physicians. Although this prototypical approach rapidly provides important information, it risks devaluing other details that may be essential to patients’ identities and clinical care. The “present illness” does not exist in a vacuum, and is, instead, on a continuum of health, which is in turn inextricably linked to priorities, preferences, and individual characteristics that cannot be adequately captured in traditional “social history” sections. It is important that EHRs have collaborative, integrated spaces capturing not just histories of “present illness,” but histories of health. And who better to help tell those histories than patients themselves? The EHR’s narrative spaces should be remodeled to allow patients to share their voices so that medical records reflect not only what physicians deem important but what our patients deem important, as well.

What might this look like? Consider the contemporary way in which many people craft personal narratives—through social media platforms. Anyone with a Facebook or Instagram account is expert at creating succinct personal profiles using adjectives, favorites, and photos designed to be shared with and quickly assimilated by viewers. Unlike today’s EHR, these platforms are designed for efficient communication and human connection. As forms of digital communication, EHRs and social media platforms are more similar than they are different. It makes sense to leverage this concordance to personalize clinical documentation in a way that is more satisfying to both clinicians and patients. Think of a personal “snapshot,” for instance, an easily accessible tab in the EHR where patients could create and store their profile of personally important things they would like their doctors to know—family photo, preferred way to receive information, names of loved ones, and upcoming milestones. Such “snapshots” could immediately humanize episodic acute care encounters; an emergency physician, for instance, would have instant access to details that would facilitate a more personalized care encounter. Similarly, such “snapshots,” evolving over the course of a patient’s relationship with their primary care provider, would lend increased depth and intimacy to long-term care relationships.

Making All Voices Heard

Patients might also be invited to contribute their own “present illness” narrative which could be incorporated into the chart. Wait times in clinics or emergency departments could be leveraged for this purpose. Patient-driven written illness narratives designed in partnership with automated algorithms have been preliminarily demonstrated to have higher quality and utility than physician-documented histories (5). Such approaches could spare clinicians some documentation burden and focus face-to-face interaction on priorities identified by the patient, while minimizing clinician interruptions that occur when interviewing is driven by documentation needs.

Beyond the template of the EHR, however, allowing patients to directly contribute their own narrative without an intermediary may capture emotion and nuance rarely contained in a standard medical note. The development of systems where patients are able to input their illness narratives in different languages and formats (in short written, audio or video form, for instance) may allow patients who are differently abled, non-English speaking, or with limited literacy to be heard on their own terms. What’s more, giving patients a voice in the health narrative also means giving a voice to patients who are institutionally disenfranchised or discriminated against, including patients of color, migrants, and the elderly. Stigmatizing language, copy-pasted notes, flags, and icons in the EHR have the potential to perpetuate harmful biases (6,7); making space for personal narratives in recorded medical dialogues may be an important step in helping physicians resist entrenched stereotypes and institutional racism.

Possibilities abound to harness technology to rehumanize physician–patient encounters. This must begin by changing patients’ and physicians’ relationship with the EHR. Although resisting the very real negative impacts that have accompanied the era of electronic documentation, this is an ideal moment of destabilization to critically examine how to listen to patient stories, what to value in those stories, and how much power to give patients in charting their own narrative trajectories through illness and health. The medical record can be viewed as a collaborative document in which patients feel an ownership stake which goes beyond their mere legal right to access it. We have to remember that EHR templates are holding up a mirror; they are a reflection of the way physicians have traditionally “taken” the patient’s history. Instead, the history can be received without sacrificing the quality of clinical reasoning. We must leverage technology to partner with patients and software teams to create inclusive avenues for patients to produce modern, uniquely human EHR profiles and craft their own histories of present illness.

It might even be fun to open up a patient’s chart. Imagine that.

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