
Perspective

Problems with the problem list: challenges of transparency in an era of patient curation

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ABSTRACT

In recent years, the OpenNotes movement and other changes in healthcare have driven institutions to make medical records increasingly transparent. As patients have begun to question and request changes to their Problem Lists, clinicians have come to face the ever more frequent challenge of discerning which changes to make and which to refuse. Now clinicians and patients together choose the list of problems that represent the patient’s current state of health and illness. As the physician’s role slides closer to consultant and the medical paternalism of the twentieth century falls further into the background of our technology-infused present, who holds the power of delineating a patient’s clinical identity? This paper examines the ethical and practical dimensions of this question and proposes a research agenda that aims to answer it. Such explorations are essential to ensuring that the physician remains relevant to patient’s notions of health, illness, intervention, and healing.

Key words: problem list, transparency, OpenNotes, patient autonomy, shared decision-making, ethics

When she presented to our infectious diseases clinic, Jane had suffered from intense and debilitating pruritus for more than 2 years. The 45-year-old woman described itching and crawling sensations over her arms and scalp that prevented her from sleeping, relaxing, or concentrating—she had even quit her job. She explained that she believed that she had tiny parasites moving on her skin and repeatedly brought in skin and fiber samples for evaluation. None of the samples revealed any parasites. In the setting of these symptoms, she denied any travel or history of exposures putting her at risk for parasite infection. Furthermore, her husband and two children had no similar symptoms. Exam was notable only for excoriation across arms and scalp. Desperate to do something to relieve her infestation, she purchased veterinary grade antiparasitic medications (horse ivermectin) on the internet and started self-

medicating. Multiple dermatologists and infectious diseases specialists had told her that there was no evidence of infestation and that her experience of pruritus and belief that she was infested with parasites were instead a delusion. Given the clinical picture, our infectious diseases team diagnosed her with delusional parasitosis and added the diagnosis to her Problem List in the electronic medical record. Certain that she was actually infested with parasites, Jane submitted a formal request to our Health Information Management Department to remove “delusional parasitosis” from her Problem List. Jane’s story came to our attention in mid-2018, when we—an interdisciplinary team of physicians and administrators—were asked by our institution to develop a “how to” guide for clinicians on managing discrepancies in and disputes over contents of a patient’s Problem List.

In recent years, the OpenNotes movement has driven institutions to make medical records increasingly transparent to patients.¹ Patient electronic health record (EHR) interfaces, such as the Epic MyChart or Cerner HealthLife patient portals, have made it easy for patients to view and request changes to their medical records. Though patient requests to modify their lists of diagnoses is not at all new, with the advent of EHRs and concomitant clinical transparency, the ease of patient access to a wide variety of data has made requests far more frequent. Over the last few years, our institution has been tracking amendment requests, and we have noted an increase in the number of formally submitted Problem List requests regarding diagnoses. Amendment requests are not always clear-cut; clinicians and patients disagree over whether an amendment accurately reflects the patient's condition.² As patients question the Problem List, clinicians face the ever more frequent challenge of discerning which changes to make and refuse. To describe the collaborative process that we have witnessed in our institution by which providers and patients negotiate the Problem List, we have coined the phrase: the *cocuration of clinical identity*.

At a historical moment in which Instagram feeds, Facebook profiles, and LinkedIn bios are central to people's identities, not just youth but also adults constantly and iteratively adjust their virtual presences.³ This same process of interactive self-representation applies to the Problem List. Not only do clinicians compile a list of problems that represents patients' current states of health and illness—but patients, too, can choose a curated collection of conditions. The capacity to curate one's clinical self is intensified by the increasingly unmediated access to medical information and direct-to-consumer tests and screens. Patients can order their own complete blood count (CBC), procure their own whole genome sequence, and diagnose their own arrhythmia by electrocardiogram (ECG)—with notably highly variable scientific and clinical accuracy.⁴ Working through the patient portal, patients can then choose to add or remove a diagnosis from the “Current Health Issues” interface (the patient's version of the Problem List) based on new privately acquired laboratory findings. As the physician's role slides closer to consultant and further from authority, the medical paternalism of the twentieth century falling further into the background of our technology-infused present, where should we draw the line in terms of who holds the power of delineating a patient's clinical identity?

This challenge has significant ethical implications. The extent to which control of the Problem List content should reflect shared decision-making versus should fall under the purview of the clinician (per traditional understandings of physician authority) has yet to be determined. Accordingly, clinicians are looking to their institutions for guidance on how to determine what should and should not be amended. As we set out to create a practical tool for resolving disputes, our analysis divided Problem List discrepancies and disputes into four categories: 1) Factual errors (eg, left rather than right knee osteoarthritis), 2) outdated problems that have since resolved (eg, obesity that has resolved due to significant weight loss), 3) patient preference to remove actual problems from the Problem List (ie, problem that is accurate and acknowledged by the patient, but the patient does not want visible on the Problem List), and 4) disagreement between patient and provider over whether a Problem List item accurately reflects the patient's problem (eg, Jane's story of a diagnosis of parasite infection by patient versus delusional parasitosis by clinician). Requests for amendments in categories 3 and 4 may be driven by concerns about risks to privacy and confidentiality (from family, other clinicians, and/or insurance companies) or psy-

chological distress from being labeled with a particular problem. Though discrepancies arise frequently over simple issues (categories 1 and 2), ethical uncertainty abounds in categories 3 and 4. Of course, disagreements increase when a sensitive diagnosis is in question, such as sexually transmitted infections, mental illnesses, reproductive issues, and gynecologic or urologic problems.

We quickly discerned that the fundamental challenge in resolving such disputes is balancing the need to ensure clinical accuracy of the Problem List against the importance of encouraging patients to engage with their health records. The Problem List has the potential to be a powerful tool for providing quality patient care. When used correctly, it distills the key elements of the medical history, enabling a provider to determine what really matters within moments of opening the EHR.^{5,6} Despite its possibilities, the Problem List can quickly become inaccurate, exactitude compromised under the pressures of relative value units (RVUs) and clinical efficiency, the allure of “copy and paste,” demands to label problems in easily billable ways, and a lack of time to ponder and update the list with precision. Maintaining the right inputs to the Problem List is challenging; with too much input from too many sources (clinicians from multiple disciplines and patients alike), its comprehensiveness can be its Achilles heel. Ensuring that the Problem List accurately represents a patient's health status—balancing inclusiveness and specificity—is a prerequisite not only for maximizing clinician efficiency but, even more importantly, for ensuring patient safety. At the same time, transparency is essential—legally, ethically, and practically. The Health Information Portability and Accountability Act (HIPAA) Privacy Rule grants patients the right to review their medical records and request amendments to them. Moreover, empowering patients to attend to and request changes to their medical records can improve the accuracy of the medical record, increase patient-provider engagement, improve patient satisfaction, enhance patient understanding of health issues, and promote patient follow-up for various health problems.²

Some may argue that clinical accuracy is nonnegotiable and that we must, therefore, prohibit patient curation in order to ensure biomedical truth. Even in the current age of patient autonomy, physician expertise, experience, and access to resources make the playing field of supposedly shared decision-making uneven.⁴ On this basis, one could argue that only the clinician should be determining a patient's health issues on the Problem List. Nonetheless, as Kilbride and Joffe point out, the clinician's role has already begun to shift, making the physician a consultant who helps to interpret test results or choose a subspecialist, a proceduralist who performs diagnostic and therapeutic interventions that patients cannot do themselves, and a gatekeeper—no longer to the simpler diagnostic tests (eg, ECGs), but to follow-up services including more complex diagnostics, and to referrals (eg, catheterization by an interventional cardiologist).⁴ We believe that the question is not whether the bidirectional curation we have begun to witness should occur, but rather how we, as individual clinicians, as healthcare institutions, and as a society, should respond to it.

We identify 3 competing “truths” at play: the scientific truth, the clinical truth, and the patient's truth. The scientific truth is the genomic sequence, the thickened heart muscle, and the family history of BReast CAncer gene (BRCA)-mediated ovarian cancer. The clinical truth is the diagnosis of Huntington's disease caused by a mutation, the diagnosis of hypertrophic cardiomyopathy indicated by the ECG and confirmed by echocardiogram, or the labeling of predisposition to ovarian cancer. Finally, the patient truth—the way the person whose body has been analyzed and interpreted perceives all of the

above, the conclusions patients and caregivers draw as they make sense of diagnoses and predispositions—is the acceptance of inevitably dying at a young age from an untreatable inherited condition, of the anticipation of possible sudden cardiac death for oneself and one’s progeny, and of the management of risk for developing ovarian cancer.

Of course, the ramifications of each diagnosis included or not included on the Problem List reach beyond the patient’s perception of oneself and one’s health. Diagnoses can influence payment and access, including insurance coverage, availability of resources (eg, a diagnosis of “cerebral palsy” qualifying a patient for a spectrum of resources not available to someone with solely “global developmental delay”), or lack thereof (eg, society deeming in vitro fertilization inappropriate for a patient with a known severe genetic mutation). Such ripple effects are the sequelae that make the Problem List—its inclusions and exclusions—bear so much weight from the perspectives of patients, families, physicians, hospital systems, and payers.

Recognizing that this phenomenon will no doubt continue to intensify, how should we navigate the doctor-patient relationship in an era of clinical curation? Where and how do we open up space for dialogue between the scientific “truth” that is the Problem List and the patient-centered “truth” that is the patient’s view of “Current Health Issues” on the patient portal? Where and how do clinician and patient autonomy interact, and which “truth” prevails in this time of patient empowerment? In an era of patient access and autonomy, these questions are crucial to consider if we hope for the physician—and for modern biomedicine at large—to remain relevant to patient’s notions of health, illness, intervention, and healing. Jane’s diagnosis of delusional parasitosis was not and should not have been removed from her Problem List, given that understanding her self-perception of infestation not confirmed by biological testing is critical for clinicians caring for her. Nonetheless, acknowledging Jane’s truth and experience of parasitosis through clearly protocolized processes for requesting Problem List amendments is crucial to affirming Jane’s dignity and remaining in dialogue with the patient—the first step in shared decision-making.

Given the immediacy of the need to answer—or at least deliberate over—such questions in the face of technology-mediated patient EHR engagement, we call for research investigating the challenges of Problem List deliberations. We need qualitative studies of both patient and physician perspectives on why and how the Problem List should be controlled and how that control should be mediated, as well as quantitative studies examining the extent of the challenge across healthcare institutions nationwide: How many disputes have arisen since the introduction of patient interfaces for questioning and requesting changes to the Problem List?

At the Cleveland Clinic, our team has embarked on this mission, starting with quantifying the number of Problem List change requests over time and characterizing them as factual errors (category 1), outdated and/or resolved problems (category 2), patient preference to remove actual problems from the Problem List (category 3), or disagreement between patient and provider over whether a Problem List item accurately reflects the patient’s problem (category 4). We then developed a “How To” tool for providers entitled “Problem List Errors, Discrepancies, and Disputes: A Quick ‘How to’ Guide for Providers” that we rolled out across the institution in September 2019. The guide offers clinicians an overview of the challenge of patient requests for Problem List revisions, notes important nuances to consider in Problem List disputes (ie, the intention of the Problem List as a tool for the distillation of the current state of a patient’s health issues, how and by whom the Problem List is visible,

and the specificities of visibility of sensitive diagnoses), provides sample case studies of disputes, and recommends specific steps for engaging patients in shared decision-making around revision requests.

Very much still in the process of integrating feedback from clinicians across our institution about the utility of this tool and continuing to improve our process for mediating Problem List disputes, we eagerly welcome recommendations from other institutions. Might there be technical solutions for integrating processes and outcomes of clinician- and patient-controlled Problem List curation beyond the still relatively separate interfaces on the patient portal and EHR? Collaborations with other institutions are crucial not only in enhancing our process but also in addressing the challenge of Problem List disputes nationwide, and we envision future collaborations among healthcare systems, government entities, and EHR vendors. To embark on this collaborative mission, we welcome dialogue with other institutions to help determine the best way forward when there are ethically uncertain Problem List disputes. We imagine this leading to a registry of Problem List disputes and an opportunity for further research and analysis. As patient empowerment continues to evolve, we aspire to work toward a fair, clinically accurate, and respectful approach that will balance the needs of multiple stakeholders. We look forward to learning together and hope colleagues interested in joining forces will email the corresponding author with ideas for collaboration.

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AP is the corresponding author. AP, KE, RL, EK, and JO conceptualized and designed the work. AP and JO analyzed and interpreted the data for the work. AP drafted the manuscript for publication. AP, KE, RL, EK, and JO critically reviewed and revised the manuscript for important intellectual content and approved the final version of the manuscript before submission for publication. AP, KE, RL, EK, and JO agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST STATEMENT

None declared.

REFERENCES

1. Wolff JL, Darer JD, Berger A, *et al*. Inviting patients and care partners to read doctors’ notes: OpenNotes and shared access to electronic medical records. *J Am Med Inform Assoc* 2017; 24 (e1): e166–72.
2. Baranowski MLH, Chisolm S, Stoff BK. Patient requests to alter the medical record. *J Am Acad Dermatol* 2019; 81 (4): 1032.

3. Lorenz R. Surgical innovation in the age of social media. *The Tincture Collective* 2017. <https://tincture.io/surgical-innovation-in-the-age-of-social-media-71e6625ac2f2#.irxyt1fxv> Accessed November 25, 2019
4. Kilbride MD, Joffe S. The new age of patient autonomy: implications for the patient-physician relationship. *JAMA* 2018; 320 (19): 1973–4.
5. Gawande A. Why doctors hate their computers: digitization promises to make medical care easier and more efficient, but are screens coming between doctors and patients? *The New Yorker* 2018; doi: 10.1162/POSC_a_00184.
6. Simons S, Cillessen F, Hazelzet JA. Determinants of a successful problem list to support the implementation of the problem-oriented medical record according to recent literature. *BMC Med Inform Decis Mak* 2016; 16 (1): 102.