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Dermatology in an Age of Fully Transparent Electronic Medical Records

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More than 4 decades have passed since the call for "giving patients their medical records" was first proposed to increase patient engagement in health care delivery.[1]Today, this vision —once considered radical—is quickly becoming reality, with millions of Americans routinely accessing their medical records through web-based patient portals.[1]

The electronic health record content that patients can access online is expanding to include physicians' documentation of patient visits. Recent studies evaluating OpenNotes, a patient-centered initiative enabling online access to providers' clinical notes, have demonstrated high levels of patient utilization and improved self-reported understanding of care planning and medication adherence, resulting in patients "feeling more in control of their health care."[1] One year after implementation of OpenNotes in 3 diverse health care environments in 2010 (Beth Israel Deaconess Medical Center in Boston, Massachusetts; Geisinger Health System in northeastern and central Pennsylvania; and Harborview Medical Center in Seattle, Washington), more than 99% of patients wished to have ongoing online access to clinicians' notes, paralleled by similar rates of primary care provider satisfaction.[1] Open-access notes have since become standard of care at several large health care systems,[2] including the Veterans Health Administration; as of January 2014, more than 1.4 million veterans have registered for full online access to their clinical notes.[3]

However, medical specialties may face distinct challenges consequent to adoption of open-access medical records. As more patients seek—and demand—comprehensive online availability of open-access notes, what will this mean for the field of dermatology? We

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believe the following issues merit particular attention among dermatologists in the era of medical record transparency.

Clinical Documentation

All medical specialties use technical terminology for detailing disease symptoms and diagnoses that may be difficult for patients to understand. However, the lexicon categorizing the litany of dermatologic disorders may prove especially difficult for patients to meaningfully interpret. For example, dermatology routinely uses Latin and ancient Greek in describing and diagnosing diseases, which may raise additional cognitive hurdles for patients and potentially result in confusion.

Although English equivalents may be available for certain diseases (eg, “wart” for verruca vulgaris, “athlete’s foot” for tinea pedis, “hives” for urticaria), other conditions may have no alternative denotation. What might a patient think when reading a note stating she has suspected lichen planus? Or acanthosis nigricans? Or pityriasis lichenoides et varioliformis acuta? While patients may be able to use the Internet to gain a better understanding of these and other skin disorders, ideally this information would also be appropriately communicated in an open-access medical record, personalized to each patient’s needs and clinical condition.

While dermatologists should continue to use precise language when documenting clinical encounters, recognizing patients as new audiences to the medical record may require adjunctive descriptions and contextualization of certain diseases. Likewise, unnecessary abbreviations (eg, BCC, CTCL, MC) may need to be avoided in favor of using complete terms (basal cell carcinoma, cutaneous T-cell lymphoma, molluscum contagiosum, respectively) to enhance clarity.

Value-Laden Terminology

Like other clinicians, dermatologists must also reconsider use of terms that may be misconstrued as judgmental by patients. This includes medical jargon, such as“patient denies” or “patient is a poor historian,” as well as subjective descriptions that may have unnecessarily negative connotations, such as “patient is sick-appearing” or “patient is frail and elderly.” These phrases may need to be replaced with neutral language, such as “patient states that he has not,” “patient cannot recall,” or “patient appears ill.” Similarly, terms such as *neurotic excoriations*, *delusional parasitosis*, *trichotillomania*, and other potentially sensitive conditions will likely need to be documented with thoughtfulness, because patients may misunderstand their use without sufficient explanation.

Dermatopathology Reporting

A recent ruling by the Department of Health and Human Services[4] in February 2014 now allows patients direct access to their medical laboratory reports. This decision reverses prior limitations within the Clinical Laboratory Improvement Amendments of 1988 (CLIA) permitting only “authorized persons”—as defined by state law—access to this information. Previously, CLIA-related information was exempted from the Health Insurance Portability and Accountability Act of 1996, leaving patients residing in 36 states without explicit authorization to procure their own laboratory records. This regulatory change applies to all CLIA-certified dermatopathology laboratories and Mohs surgical suites, which are now legally mandated to provide dermatopathology reports directly to patients on request, thereby eliminating administrative barriers and other hurdles that may have otherwise restricted patient access to this information.

Given that prior research suggests that surgeons misunderstand pathology reports approximately 30% of the time,[5] the risk of patients also misinterpreting these reports is substantial. Like clinical documentation, dermatopathology reports may prove challenging for patients because of technical terminology. Patients may find the organization of dermatopathology reports confusing, mistaking the final diagnosis with information contained in the histologic description. How will a patient react, for example, on reading that her biopsy showed“ a perivascular lymphocytic infiltrate with prominent eosinophils, consistent with a dermal hypersensitivity reaction”?

Moreover, how will patients respond to dermatopathology reports that express diagnostic uncertainty or use ambiguous diagnostic terminology? Is there potential for harm when a patient reads that she has a “moderate to severe dysplastic nevus” or an “atypical melanocytic proliferation of uncertain biologic potential”? Presentation of unclear pathologic data may, for example, lead patients to request additional, unneeded biopsies, excisions, or other procedures.

Furthermore, how will dermatopathologists reply to patients who seek additional clarification from them regarding their reports? Should they defer to the biopsying clinician or provide their own opinion directly? What if patients discover information in the “reason for biopsy/clinical impression” section of dermatopathology reports that was not previously communicated to them? Should dermatopathology reports also contain treatment recommendations, eg, suggested margins for surgical excision of melanocytic neoplasms, which may conflict with advice provided to patients by their physicians?

Unfortunately, there may be no easy answers to these questions, highlighting the need for optimal communication among clinicians, dermatopathologists, and now our patients. Lack of uniform pathology reporting in general,[5] and the complex terminology used in our field suggest that the road ahead may be bumpy. However, recent efforts to standardize formatting of pathology reports,[6] as well as diagnostic categories of melanocytic neoplasms, may be important steps forward.[7]

Conclusions

Dermatologists should consider preparing for the impact of fully transparent medical records on their clinical practice. Patients will continue to exert greater ownership of their health information, and clinicians will surely face some, if not all, of the issues described herein, in addition to future unknown challenges.

Reaching the goal of transparency requires reconceptualizing the role of the medical record in health care delivery. While it will undoubtedly remain a vehicle for professional documentation and interclinician communication, the open-access medical record will also serve as a potent mechanism for patient engagement and health information dissemination. Dermatologists may benefit from the experiences of colleagues at institutions that have successfully transitioned from closed to open medical record systems.[2] Although best practices to achieve the latter are still evolving, educational toolkits are currently available for those interested in learning more about the open-notes approach to medicine.[2]

We believe the medical record transparency movement will continue to grow. Our hope—and expectation—is that this new age of open access to clinical notes will empower dermatologists and patients alike to achieve stronger relationships, better care, and improved health.

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