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Dermatopathologists' Experience With and Perceptions of Patient Online Access to Pathologic Test Result Reports

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IMPORTANCE Many patients presently have access to their pathologic test result reports via online patient portals, yet little is known about pathologists' perspective on this topic.

OBJECTIVE To examine dermatopathologists' experience and perceptions of patient online access to pathology reports.

DESIGN, SETTING, AND PARTICIPANTS A survey of 160 dermatopathologists currently practicing in the United States who are board certified and/or fellowship trained in dermatopathology was conducted between July 15, 2018, and September 23, 2019. Those who reported interpreting skin biopsies of melanocytic lesions within the previous year and expected to continue interpreting them for the next 2 years were included.

MAIN OUTCOMES AND MEASURES Dermatopathologists' demographic and clinical characteristics, experiences with patient online access to pathologic test result reports, potential behaviors and reactions to patient online access to those reports, and effects on patients who read their pathologic test result reports online.

RESULTS Of the 160 participating dermatopathologists from the 226 eligible for participation (71% response rate), 107 were men (67%); mean (SD) age was 49 (9.7) years (range, 34-77 years). Ninety-one participants (57%) reported that patients have contacted them directly about pathologic test reports they had written. Some participants noted that they would decrease their use of abbreviations and/or specialized terminology (57 [36%]), change the way they describe lesions suspicious for cancer (29 [18%]), and need specialized training in communicating with patients (39 [24%]) if patients were reading their reports. Most respondents perceived that patient understanding would increase (97 [61%]) and the quality of patient-physician communication would increase (98 [61%]) owing to the availability of online reports. Slightly higher proportions perceived increased patient worry (114 [71%]) and confusion (116 [73%]). However, on balance, most participants (114 [71%]) agreed that making pathologic test result reports available to patients online is a good idea.

CONCLUSIONS AND RELEVANCE Dermatopathologists in this survey study perceived both positive and negative consequences of patient online access to pathologic test result reports written by the respondents. Most participants believe that making pathologic test result reports available to patients online is a good idea; however, they also report concerns about patient worry and confusion increasing as a result. Further research regarding best practices and the effect on both patients and clinicians is warranted.

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More than 30 million US patients presently have access to their medical records via online portals.¹ These portals allow patients to review clinician notes, test results, and other aspects of their medical record. As online portals become commonplace, potential benefits and challenges must be considered. Patients and clinicians agree that reading clinicians' notes online may help patients feel more in control of their health and be better prepared for visits.^{1,2} However, both groups also report concerns about patient worry and confusion when reviewing complex health information they do not understand.^{2,3}

Patient access to online pathologic test result reports may facilitate a more active role for patients in their medical care⁴;

Table. Dermatopathologists' Demographic and Clinical Characteristics Including Experience and Perception About Patients Having Online Access to Pathologic Test Result Reports

Characteristic	No. (%)
Demographic Characteristics	
Sex	
Male	107 (67)
Female	51 (32)
Prefer not to answer	2 (1)
Age, y	
<40	29 (18)
40-49	65 (41)
50-59	43 (27)
≥60	23 (14)
Clinical Experience	
Affiliated with an academic medical center	
No	75 (47)
Yes	
Adjunct/affiliated clinical faculty	49 (31)
Primary appointment	36 (23)
Residency program completed	
Anatomic/clinical pathology	88 (55)
anatomic pathology	28 (18)
Dermatology	52 (33)
Other	3 (2)
Patient Online Access to Pathology Reports^a	
Are you aware that some patients have online access to their pathology reports?	
No	11 (7)
Yes	149 (93)
In general, making pathology reports available to patients online is a good idea^a	
Disagree	15 (9)
Somewhat disagree	31 (19)
Somewhat agree	60 (38)
Agree	54 (34)
Do patients have online access to the pathology reports that you write?^a	
No	59 (37)
Yes	53 (33)
Unsure	48 (30)
Have patients contacted you directly about pathology reports that you have written?^a	
No	69 (43)
Yes	91 (57)

^a Wording used in the survey.

Key Points

Question What are dermatopathologists' experiences and perceptions regarding patients having online access to pathologic test result reports?

Findings In this survey study of 160 dermatopathologists, 57% reported that they have been contacted by patients about their pathologic test result reports. Although most respondents believe that having online access to these reports will help patient understanding of their medical issues (61%) and increase the quality of patient-physician communication (61%), most also reported concerns about increasing patient worry (71%) and confusion (73%).

Meaning As more patients gain online access to their pathologic test result reports, it is important to consider how to optimize these reports to improve comprehension by patients and reduce potentially negative consequences.

however, reports are often written at a reading level above most patients' abilities.^{5,6} Pathologic test reports are challenging even for clinical practitioners to understand. A previous study has suggested that pathologists consider adapting reporting styles in an era of increasing patient access.⁷

Little is known about pathologists' perspectives on patient online access to pathologic test result reports. We examined dermatopathologists' experiences and perceptions of current patient access. Exploring clinicians' perspective is necessary to understanding and anticipating potential consequences of increasing patient access to pathologic test result reports.

Methods

The present study is drawn from a larger nationwide study evaluating dermatopathologists' diagnoses of melanocytic skin lesions. The overall study included completing an online survey and interpreting glass slides of melanocytic lesions. Only data from the online survey are reported in the present study. All procedures were approved by the institutional review boards of the Fred Hutchinson Cancer Research Center, Seattle, Washington, and the David Geffen School of Medicine at the University of California, Los Angeles, and are Health Insurance Portability and Accountability Act compliant. The participants provided informed consent; with their participation, they had the opportunity to receive continuing medical education credits free of charge.

Pathologist Identification and Recruitment

We identified potential participants in 40 states (excluding 10 states recruited from the previous melanoma pathology study by Elmore et al⁸) who were board certified in dermatopathology and had adequate contact information, generated by Direct Medical Data, LLC databases. To be eligible, participants had to be currently practicing in the United States, board certified and/or fellowship trained in dermatopathology, interpreting melanocytic skin biopsies within the previous year, and expecting to continue interpreting melanocytic skin lesions for

Figure 1. Responses of 160 Dermatopathologists Asked "If Patients Were Reading My Pathology Reports Online, I Would"

the next 2 years. Once eligibility was verified, individuals were invited to enroll in the study and completed the survey between July 15, 2018, and September 23, 2019.

Survey and Data Collection

The survey was developed with a panel of dermatopathologists (M.W.P., S.R.K., R.L.B., D.E.E.). The survey was administered online using REDCap⁹ and collected participants' demographic characteristics and clinical information, perceptions of patient access to online pathologic test result reports, thoughts about medical malpractice, opinions on standardized taxonomy for melanocytic skin lesions, perceptions about second opinions in clinical practice, and patient safety. Six questions were asked about participants' experiences with patient access to online pathologic test result reports; these queries are detailed in the Table, Figure 1, and Figure 2. Specific survey questions relevant to online pathologic test result reports are listed in the eAppendix in the Supplement.

Statistical Analysis

Descriptive statistics, including means, SDs, and frequencies of participants' responses were calculated. Data analysis was conducted using SAS, version 9.4 (SAS Institute Inc).

Results

Of the 702 potential participants whom we attempted to contact, 216 individuals had incorrect contact information. Of the remaining 486 individuals, 226 dermatopathologists were verified as eligible for participation; 160 of these respondents (71%) subsequently enrolled and completed the online survey.

The Table summarizes the demographic and clinical characteristics of the 160 participants, including their experience with patients' online access to pathologic test result reports. Most participants were male (107 [67%]), with a mean (SD) age of 49 (9.7) years (range, 34-77 years); 36 participants (23%) had a primary academic appointment and 49 participants (31%) were adjunct/affiliated clinical faculty. Most participants completed a residency program in anatomic/clinical or anatomic pathology (116 [73%]), followed by dermatology (52 [33%]). Participants' practices were in 34 US states distributed among US Census Bureau Regions as follows: Northeast (19%), Midwest (31%), South (40%), and West (10%).

Almost all participants (149 [93%]) were aware that some patients have online access to reports. When asked specifically whether patients have online access to reports that the

Figure 2. Responses of 160 Dermatopathologists Asked "How Would the Following Change Due to Patients Having Online Access to Their Pathology Reports?"

participants write themselves, participants responded yes (53 [33%]), no (59 [37%]), and unsure (48 [30%]) at similar rates. Just more than half (91 [57%]) reported that patients have contacted them directly about pathologic test result reports.

Participants were queried about their potential behaviors and reactions if patients were reading their pathologic test result reports online (Figure 1). Some participants noted that they might change the way they write reports by decreasing their use of abbreviations and/or specialized terminology (57 [36%]) and by changing the way they describe lesions suspicious for cancer (29 [18%]). While most respondents reported being open to receiving calls from patients (97 [61%]), 39 respondents (24%) reported needing specialized training in communicating with patients.

Participants were also queried about consequences on patients reading pathologic test result reports online (Figure 2). More than half reported that patient understanding of medical issues (97 [61%]) and the quality of patient-physician communication (98 [61%]) would increase or cause no change (46 [29%] and 44 [28%], respectively). Most participants also thought patient worry (114 [71%]) and confusion (116 [73%]) would increase. However, most participants (114 [71%]) agreed that making pathologic test result reports available to patients online is a good idea (Table).

Discussion

Although surveyed dermatopathologists perceived both positive and negative consequences associated with patient online access to pathologic test result reports, their overall perception of such access was positive, despite the fact that concerns for potential negative effects (patient worry and confusion) were slightly more prevalent than for potential positive effects (improved patient understanding and patient-physician communication).

A primary concern about patient online access to test results is that patients can view their results without a clinician's interpretation.^{4,10,11} Electronic health records can be configured to release results only after a specified amount of time¹¹ to ideally allow clinicians time to provide results to patients with interpretation and clinical context. However, such time delays may not be implemented or clinicians may not review results with patients within the allotted time. Pilot studies suggest that it may be beneficial to create programs that facilitate face-to-face communication between patients and pathologists, thereby increasing patient understanding of pathologic test result reports and diagnoses.¹²

More than half of surveyed dermatopathologists reported being open to receiving calls from patients, with one-quarter reporting that they need specialized training in communicating with patients. Prior studies have suggested that pathologists need improved communication skills, as communication is often not a formal component of their training.^{12,13} As reporting transparency increases, improved communication skills will be necessary for dermatopathologists to explain test results to patients clearly and prepare them for potential patient questions and reactions.

Limitations and Strengths

There are potential limitations in this study. By surveying participants about online pathologic test result reports, we are limited to the questions that were asked and did not observe actual clinical practice. We surveyed specific subspecialists (dermatopathologists); the results of this study may not generalize to other pathology practices. Study strengths include a high survey response rate (71% of eligible invitees) and a wide variety of represented practice types and locations among respondents.

Conclusions

Dermatopathologists surveyed in this study believe that patient access to online pathologic test result reports is a good idea; nonetheless, they also agree that there are potential negative consequences to such access. Our findings suggest that most practitioners would not change their report content or style owing to patients reading their pathologic test result reports online and that a substantial proportion already have patients who read their reports and call the physicians to discuss the results. As patient access to pathologic test result reports increases, it is important to consider best practices to minimize potential negative consequences for patients and clinicians. To mitigate patient confusion, one possible solution would be use of a standardized classification tool, such as MPATH-Dx, when reporting on challenging melanocytic lesions.¹⁴ Further quantitative analyses are needed to determine the rates at which online access to pathologic test result reports create worry or confusion for patients.

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