"Please Help Me See the Dragon I Am Slaying"

Implementation of a Novel Patient-Pathologist Consultation Program and Survey of Patient Experience

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• ***Context.***—**Pathologists evaluate human disease and teach medical students, residents, and clinicians. Historically recognized as the "doctor's doctor," pathologists are well suited to be a direct patient resource of individualized, accurate information.**

Objective.—**To develop and implement a pathology consultation service whereby patients review their tissue slides directly with pathologists.**

Design.—**A pathologist conducted patient consultations, reviewing biopsy or surgery findings on a multiheaded microscope or computer screen. The pathologist evaluated patients' understanding of their disease and invited patients to ask specific questions. We recorded patient demographic data and assessed utilization with a short patient satisfaction survey using 6 questions with a 5-point Likert scale and 2 questions for open response.**

Results.—**A total of 31 patients came for consultation; 39% (12 of 31) were accompanied by a friend or family member. Patients' median age was 59 years, with a strong female predominance (90%; 28 of 31). The majority of patients had breast cancer (58%; 18 of 31) or hematologic malignancy (19%; 6 of 31). Of the 31 patients, the survey response rate was 58% (18 of 31). Top-box scoring demonstrated program support, with 89% (16 of 18) of respondents strongly recommending the experience to another patient. Additionally, 78% (14 of 18) strongly agreed that they felt more empowered after seeing their disease. Mean scores for Likert-based questions all were higher than 4.0.**

Conclusions.—**To our knowledge, this study is the first report of direct patient-pathologist consultation. Early data suggest that the program may provide effective patient-specific education. The high response rate and favorable assessment of the program suggest that it may be a valuable resource for some patients.**

(*Arch Pathol Lab Med.* 2019;143:852–858; doi: 10.5858/arpa.2018-0379-OA)

The relatively rapid evolution of molecular diagnosis and molecular therapeutics, and the even more recent rise of immunodiagnostics and immunotherapeutics, has provided pathologists with unprecedented opportunities to more fully engage in patient diagnosis and management. These opportunities arise on several fronts. Pathologists are active partners with other physicians, including interventional radiologists, to best ensure that adequate tissue is being provided by biopsy to allow for complete diagnostic testing, including immunostains and molecular testing, so that the team has complete information to allow for appropriate and truly personalized therapy.[1] Pathologists are also becoming effective members of diagnostic management teams, sharing with their patients and the team histologic, immunohistochemical, and molecular features of patients' diseases so patients better understand their conditions and can work with the team to make the best personalized treatment choices.[2,3] With the increasing use of online patient portals, pathologists' reports are becoming increasingly available to patients, sometimes immediately. This has provided pathologists the opportunity to speak directly with patients about their diagnoses and more frequently show the cases to patients and patients' families, either in person or via telepathology. The advent of the pathology consultation clinic, with direct patient-pathologist interaction, should therefore come as no surprise, as the time is ripe for its establishment. This additional method of direct patient interaction is timely and necessary in today's dynamic medical world, both for the betterment of patient care and for the effective and efficient use of medical resources and physician expertise.

Pathologists have directly taken steps to make ourselves more visible to patients. The College of American Pathologists has urged pathologists to be more visible, resulting in several avenues to interact directly with patients and clinical care teams.[4] Prominent among these is the See, Test, and Treat program, sponsored by the College of American

Accepted for publication August 29, 2018.
Published online November 6, 2018.

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The authors have no relevant financial interest in the products or companies described in this article.

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Pathologists Foundation, Northfield, Illinois. Social media initiatives on Facebook (Menlo Park, California), Twitter (San Francisco, California), Instagram (Menlo Park, California), and other social media platforms have extended the pathologists' voice. Pathologist outreach on Facebook support groups has shown tremendous success.[5]

Today's patients are increasingly "'e-patients', the growing population of patients who are 'equipped, enabled, empowered, and engaged in their health and health decisions.'"[6] They embrace technology as a tool to better understand diagnostic and treatment options.[7] These e-patients desperately seek credible sources for health information independent of their treating physicians. Physicians are now apomediators—facilitators for patients to navigate information without the need of a gatekeeper (eg, the primary physician), particularly with the preponderance of online resources. Studies have shown that patients prefer physicians as apomediators in order to develop a better understanding of their health.[8] On Twitter, scheduled chats now routinely occur with subspecialty experts using @lcsmchat and #lcsm "lung cancer social media" to answer patients' questions about their diagnosis and how it was made.[9]

Pathologist-patient consultation is not new. Spencer Nadler[10] wrote poignantly of his visits with one of his breast cancer patients, Hanna Balyan, in his book *The Language of Cells: Life as Seen Under the Microscope*. Recently shared by the College of American Pathologists is a valuable interaction regarding a woman with lung cancer who traveled to Newton-Wellesley Hospital, Newton, Massachusetts, to observe tissue biopsy slides with her pathologist, Michael Misialek, MD.[11] His interactions with his patient inspired this project regarding the necessary patient availability required of the modern pathologist.

Pathologists evaluate human disease and teach medical students, residents, and clinicians.[12] Pathologists have long been the "doctor's doctor" and are now charged with being a direct patient resource of individualized, accurate information. Our radiology colleagues have already begun examining their increased role in direct patient communication, with an eye toward developing "patient-centered radiology."[13]

This project sought to develop and establish a pathology consultation service to educate patients directly. Following implementation, a retrospective study was performed to evaluate patient response. We report early results on utilization and patient response to consultations connecting patients to pathologists at a community hospital.

METHODS

Establishment and Patient Recruitment

Hospital administration, risk management, the marketing department, and relevant practice managers evaluated the feasibility of a patient-pathology consult program. Following formal approval, the project was launched, and information promoting the pathology consult program to patients and their families was distributed institutionally, including within the department, the hospital, and the cancer center, as well as posted online and distributed as flyers (Figure 1). The program was promoted at various venues, including tumor board, cancer committee, and medical executive committee meetings. A program focused on cancer center physicians, breast health navigators, and nurse practitioners was established to educate them about the pathology consult program functions and to share the information being provided to the patient. The breast cancer service incorporated the patient-pathology consult program flyer into a packet of information routinely provided to all patients diagnosed with breast cancer. In addition, the breast cancer support group at Lowell General Hospital (Lowell, Massachusetts) included a discussion about this program by the nurse educator at the cancer center. Either the patient or the patient's oncology team could initiate the consultation process by contacting the pathology department.[14]

Preparation

The pathology department used a standard script to schedule the patient's appointment at a mutually convenient time, with preference given to times adjacent to other existing appointments. Staff preparation time for patient consultation was 15 minutes, in order to gather slides, reports, and consent forms and to coordinate Health Insurance Portability and Accountability Act of 1996–compliant space for the consult to take place. The pathologist spent approximately 10 minutes for slide and chart review, 30 minutes for the consult, and another 5 minutes to issue a report addendum. When the patient arrived, a department team member designated to assist on that day welcomed the patient to an office space that contained a computer and a multiheaded microscope. Routine clinic check-in procedures were followed, such as confirmation of patients' identity and consent form signatures; the slides and pathology report are considered patients' medical record, as deemed by the risk management department. If the patient was accompanied by a family member, the family member was required to provide identification, and the patient was required to provide consent for the family member to be in the room.

The Patient Consultation

The consultation began with introductions, and the pathologist asked if the patient would like to look in the multiheaded microscope or preferred to view the case on a large computer screen. Next, the agenda for the appointment was set by inquiring as to whether the patient had any specific questions at the outset and establishing the patient's level of understanding of the disease. The pathologist then pointed out the patient's name on the slide and explained the tissue processing procedure and slide preparation, being careful to avoid as much medical jargon as possible. The patient was then shown normal tissue, identifying significant structures; for example, "The nucleus is the brain, and the cytoplasm is the body of the cell." Once the foundation of normal was established, the patient was shown diseased tissue; this frequently led to additional questions. The pathologist deferred questions regarding treatment to the referring physician. The patient was free to take notes, but no audio or video recording was permitted. The appointment ended with the offering of the patient's pathology report and asking if the patient had any further questions. The pathologist also gave the patient a business card and hospital administration contact information, should the patient choose to write a letter regarding the experience. Consultation complete, a department team member escorted the patient to the hospital exit. An addendum was then made to the pathology report indicating that slides were reviewed with the patient, with the date and time noted. A follow-up email was also sent to the referring clinician. The patient was sent a thank-you card for choosing to obtain his or her care at the hospital. Included with the card was a patient satisfaction survey with a prepaid return envelope. Copies of the signed consent forms were forwarded to the medical records department, and the original forms were secured in the pathology department.

Survey

A patient satisfaction survey was designed and approved by the Lowell General Hospital institutional review board. Six questions were developed with scaled responses expressed using a 5-point Likert scale ranging from strongly agree to strongly disagree. Two free-text questions were used to provide clarity and further insight into scaled questions (Figure 2). Subjects responded by mailing back the survey to the Department of Pathology. There were no

Patient Pathology Consult Program

Lowell General Hospital

Lija Joseph, MD

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Patient Pathology Consult Program

Lowell General Hospital is happy to announce a new collaborative service from our Pathology Department to enhance physician/patient communication and provide a new level of *Complete connected care*. Patients who have undergone a biopsy or other laboratory testing will have the opportunity to review their reports/slides with a free in-person consultation held in the pathology department.

Patient appointments will be with Dr. Lija Joseph. The patient's primary care team (physician, NP, etc.) will be notified of the patient request, the date and time of the consult, and have the opportunity to be present during the consultation in person or via conference call.

Consultations

To make your appointment for a free consultation with Dr. Lija Joseph, please call the Pathology Department at 978-937-6341 (x.76341). For additional information, contact Dr. Lija Joseph at Lija.Joseph@lowellgeneral.org.

Appointments can be made by calling 978-937-6341.

Consultation will be held Monday to Friday between 8:30 am – 4:30 pm

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Figure 1. *Flyer given to breast cancer patients.*

Please complete this anonymous and confidential survey and mail back in the attached postage paid envelope. We greatly appreciate your response.

Did you think there was enough time to address your questions and concerns?

5 Strongly Agree	4 Agree	3 Neither agree or disagree	2 Disagree	1 Strongly Disagree

Was the description of your biopsy results by the pathologist presented in language that was clear and understandable to you?

5 Strongly Agree	4 Agree	3 Neither agree or disagree	2 Disagree	1 Strongly Disagree

Did viewing your slides give you a better understanding of your disease?

5 Strongly Agree	4 Agree	3 Neither agree or disagree	2 Disagree	1 Strongly Disagree

Now that you have seen the disease "face-to-face" do you feel more empowered in managing your disease?

5 Strongly Agree	4 Agree	3 Neither agree or disagree	2 Disagree	1 Strongly Disagree

Would you be interested in coming back for multiple consultation sessions as part of your treatment management?

5 Strongly Agree	4 Agree	3 Neither agree or disagree	2 Disagree	1 Strongly Disagree

Would you recommend the experience to another patient?

5 Strongly Agree	4 Agree	3 Neither agree or disagree	2 Disagree	1 Strongly Disagree

What was the most memorable portion of your meeting?

Do you have any additional comments that you would like to share with us that we can use to improve the patient experience?

Figure 2. *Patient satisfaction survey.*

Table 1. Characteristics of the 31 Patients Participating in the Patient-Pathologist Consultation Program

Variable	Value
Sex, No. (%)	
Female	28 (90)
Male	3 (10)
Age, y	
Median	59
Range	32–83
Disease, No. (%)	
Breast cancer	18 (58)
Hematologic malignancies	6 (19)
Other solid malignancies	5 (16)
Nonmalignant disease	2 (6)

follow-up requests for response. The prevalence of patient characteristics and responses to the survey questions were reported, as well as median and range scores.[15–17] Survey results were analyzed using a "top-box" scoring method, which evaluates the percentage of responses selecting strongly agree to Likert-scale questions.[18–20] The mean value of responses was also calculated, and free-text response questions were not statistically evaluated.

RESULTS

From March 2017 through April 2018, Lowell General Hospital evaluated 1615 new cancer patients. Of those, 31 patients (2%) ranging from 32 to 83 years in age attended a pathologist-patient consultation to review their cases. The majority of the 31 diagnoses were of malignant diseases, including 18 (58%) breast cancer and 6 (19%) hematologic malignancy. The remaining patients were diagnosed with nonmalignant autoimmune diseases. A spouse, child, sibling, or friend accompanied 12 of the 31 patients (39%). From the 31 patient consultations, 18 surveys (58%) were received. The distribution of respondents well reflected our consult population, with the majority being women with breast cancer diagnoses (Table 1). Top-box scoring results demonstrated support for the program, with 89% of respondents selecting strongly agree when asked if they would recommend the experience to another patient. Patients were asked if they felt more empowered after seeing their disease "face to face," and 78% of survey respondents selected strongly agree (Table 2). Free-text responses confirmed the positive results as shown in Table 3.

A few common threads were identified as the service grew. Patients were curious to see their biopsies under the microscope or on the computer screen, instead of representative images online. Patients often stated a desire to see normal tissue and compare it with tumor. Questions regarding treatment rarely arose, and the consulting pathologist spoke only to the pathologist's role on the patient's care team. One patient had particular questions about molecular markers and how clinical trials and studies are designed and implemented.

A targeted approach to reach out to breast cancer patients proved to be the most effective means of engagement. Some patients had already researched their diseases online, had a science background or an interest in biology, or had considered a career in health care. In addition to survey responses, patients rated the program highly, with 4 personal notes of thanks to the pathologist and hospital patient advocacy department. Patients advocated for additional support for programs like this to hospital leadership. For example, "This was an awesome experience. I hope this program will continue to be offered. I realize that not everyone will be interested, but those of us who are, it is a valuable learning opportunity."

Patients' comments from their encounters and from the survey were notable. One patient with breast cancer said, "I know, I am about to embark on a long journey, please help me see the dragon that I am slaying." Another patient stated, "This option was never available in the olden days, this is really helpful for me." An older woman stated, "I am so proud that you are doing this, I am very proud of you being a woman, and that you are in the medical field, thanks so much for your help." Another patient stated, "I am the only grandfather alive, and I want to see my grandchildren graduate high school. Allowing me to see my tumor helps me stay motivated to understand and tackle my cancer cells." One patient requested a representative microscopic image of the tumor, printed on paper, to share with her family in South America. Also, the oncology team was very grateful, commenting, "An enhanced patient experience!" A list of more patient quotes is provided in Table 3.

DISCUSSION

Traditionally, patient-pathologist consultations have been infrequent, representing the exception rather than the rule. As such, the patient-pathologist consultation program was launched with a limited expectation of 2 to 3 patient consultations per year. In fact, it realized an average of 2 to 3 consultations per month. This program was offered free of charge to the patient. Future iterations taking into account time and materials will seek to determine formal billing practices with the establishment of corresponding Current Procedural Terminology codes. Information about this program was recently published in *CAP Today* magazine.[4]

Table 2. Top-Box Scoring and Mean Scores on the Patient Survey From the 18 Respondents

Question	Strongly Agree, %	Mean Score (Range)
Did you think there was enough time to address your questions and concerns?	78	4.7 (2–5)
Was the description of your biopsy results by the pathologist presented in language that was clear and understandable to you?	83	4.7 (2–5)
Did viewing your slides give you a better understanding of your disease?	72	4.6 (3–5)
Now that you have seen the disease "face to face" do you feel more empowered in managing your disease?	78	4.5 (2–5)
Would you be interested in coming back for multiple consultation sessions as part of your treatment management?	44	4.0 (1–5)
Would you recommend the experience to another patient?	89	4.9 (4–5)

Table 3. Selected Patient Responses to Free-Text Questions	
Question	**Response**
What was the most memorable portion of your meeting?	"Meeting [Pathologist], she is awesome. She was very patient with my questions and she described and explained in understandable language."
	"Knowing about my condition at length."
	"[Pathologist] was extremely patient and used words that I would be able to understand. She also had material for me to review on my own to understand my disease better. The most important thing [Pathologist] did was include my daughter in the learning process. I had an amazing experience, thank you!"
Do you have any additional comments that you would like to share with us that we can use to improve the patient experience?	"[Pathologist] let me see my "Dragon" so that I knew what I was fighting. It was important to me to not be afraid of the cancer but to try and learn about it."
	"This is a wonderful idea!! I have told many people about this program. Thank you [Pathologist]!"
	"I found the length of the session to be just right for me. Thank you."

Inquiries regarding the structure of the program and positive feedback have been received from pathologists across the country. Twitter correspondence has brought to light a similar service being established at Duke University (Durham, North Carolina), with the additional, laudable goal of increasing resident involvement to combat burnout.[21]

Despite the rapid growth of our service and launch of similar programs, there are still concerns. Many pathologists may fear exposure to increased medicolegal liability and potential lawsuits. Others may argue the added responsibility and time commitment is too high, and some pathologists will not want to change their practice. External critics may include treating physicians concerned about what specific information the pathologist will communicate with the patient and how it will affect the treating physician's practice.

Benefits to family members were also clearly observed during the consultations. One patient's daughter requested a referral to a primary care physician within the system. Another patient sought a cancer support group for patients of specific ethnic descent, of which the patient had not previously been aware. After local media coverage, a self-referral to the consultation service brought a new patient to our hospital.[22] Although the immediate benefit to patients of this program has been overwhelmingly demonstrated by the success of this program, long-term benefits such as improvements in compliance and outcomes will be evaluated as the program continues. After seeing the estrogen receptor positivity of her breast cancer, one patient with breast cancer noted that she would have taken her tamoxifen as prescribed had she seen her tumor cells previously. This anecdote demonstrates the potential positive effect the consultation service can have on treatment adherence and, as such, on prognosis.

The higher rate of breast cancer patient consultations is attributed to the flyer's incorporation in those patients' information packets. It may be helpful for pathology groups with a robust breast care program, or other robust program, to consider a similar program. Importantly, the hospital's accreditation site visit for National Accreditation Program for Breast Centers by the American College of Surgeons in October 2017 recognized this program as a "best practice." Such recognition strongly signals the value of this program to our colleagues. Surgeons and oncologists have stated, "This enhances the patient experience," and "Pathologists are the engine that drives the car, it is important for the patient to encounter the entire care team." These clinicians continue to show their support through referrals.

CONCLUSIONS

The early success and warm reception of the patient-pathologist consultation program powerfully demonstrates the need for pathologists to fill the vacancy in today's patients' care. It is hoped that pathologists will use this program model as a template to launch similar programs at their institutions. Pathologists' diagnoses frequently have a life-changing impact on patients and their families, and particularly in today's dynamic molecular era, at a time of precision medicine and individualized therapy, pathologists have a nondelegable responsibility to reestablish ourselves not just as "the doctor's doctor" but as the patient's doctor. The advent of patient portals, markedly improved technology, social media, and access to the Internet have massively expanded the information currently available to patients very easily. Pathologists must therefore quickly adapt to accommodate the needs of those who are eager to "see the dragon they are slaying." We must meet the patient on his or her own terms.

There is extraordinary value in these consultations for the pathologist as well. Face-to-face encounters may even have the potential to increase pathologists' diagnostic accuracy. One study involving radiologists showed that seeing a photograph of a patient at the time of reading a computed tomography scan improved their examination accuracy. It is reasonable to imagine increased pathologist face-to-face encounters with patients could similarly increase diagnostic accuracy; this is an area ripe for study.[23]

Pathologists evaluating tissue through the microscope have low-power and high-power objectives, but a pathologist looking in the microscope, educating a patient, has *real* power.

Dr Joseph would like to thank the leadership team of Lowell General Hospital and her colleagues Sonali Ayar, MD; Cheryl Ennis, MD; Bethany Tierno, MD; and Dana Semmel, MD, for their unwavering support to make this project successful. Dr Booth would like to thank Judy A. Trieu, MD, MPH, for her feedback and suggestions in the development of the patient survey.

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