A “Pathology Explanation Clinic (PEC)” for Patient-Centered Laboratory Medicine Test Results

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Abstract
This concept paper addresses communication issues arising between physicians and their patients. To facilitate the communication of essential diagnostic pathology information to patients, and address their questions and concerns, we propose that “Pathology Explanation Clinics” be created. The Pathology Explanation Clinics would provide a channel for direct communications between pathologists and patients. Pathologists would receive special training as “Certified Pathologist Navigators” in preparation for this role. The goal of Pathology Explanation Clinics would be to help fill gaps in communication of information contained in laboratory reports to patients, further explain its relevance, and improve patient understanding of the meaning of such information and its impact on their health and health-care choices. Effort would be made to ensure that Certified Pathologist Navigators work within the overall coordination of care by the health-care team.

Keywords
communication, laboratory medicine, patient-centered care, Second Flexner Century, surgical pathology

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Introduction
This is the fifth in our series of Second Flexner Century papers on innovations in medical education and health-care delivery systems, published in Academic Pathology.1-4 Surgical pathology dates back to the early 20th century, but the major advances in immunohistochemistry, laboratory medicine, molecular diagnostics, pathology informatics, and personalized medicine have occurred in the last 40 years. However, in the words of Dr Edward O. Uthman, a “paraffin curtain” has been constructed between the pathologist and the patient, referring to the fixation of many surgical pathologists on rendering diagnoses on paraffin histopathology slides.5 Uthman was regretting that surgical pathologists rarely interact directly with patients. This does not mesh well with the emerging model of “patient-centered care” in which patients become integral to decision-making processes as members of their own individual health-care teams. Nor need Uthman’s “paraffin curtain” metaphor apply exclusively to surgical pathology. Direct communication between patients and pathologists

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regarding the full spectrum of laboratory medicine test results is all too infrequent.

In this concept paper, aimed at expanding the role of pathologists in patient-centered care, we are proposing the broadening of the definition of “laboratory medicine,” making the term inclusive of all aspects of anatomic pathology, including surgical pathology in addition to what is currently defined as “laboratory medicine.” We envision the creation of Pathology Explanation Clinics (PECs) where discussing laboratory medicine test results with patients would involve “one-stop-shopping” including the integration of test results for the patients’ immediate consideration and appropriate conversations between patients and pathologists, along with relevant and necessary clarifications. We acknowledge that many practicing pathologists would require additional training in order to assume this role.

As clients of pathology services, physicians ordering diagnostic tests for their patients must grapple with the rapidly evolving diagnostic and therapeutic advances. They must continually realign, along with these advances in laboratory diagnostic technologies and medical imaging services, what they discuss with their patients. Newer models for health-care delivery could actually complicate a physician’s efforts to effectively communicate with the patient. Interdisciplinary care is now normative in the management of complex medical diseases, such as cancer. Individual members of teams, such as advanced practice nurses, might be unprepared to answer important questions about laboratory results coming from the patient within their own interdisciplinary care team. Electronic health records (EHRs) can add yet another layer of complexity to patient management. Increasingly, EHRs give patients direct access to their personal laboratory reports. Patients can bring up laboratory test results on their computers, including surgical pathology reports, and then contact laboratories directly to discuss their own test interpretations with a pathologist. However, they rarely do so. This concept article proposes an innovative approach to engaging pathologists in “patient-centered laboratory medicine.”

Pathologist-to-Patient Communication Interventions

Since the year 2000, commentaries supporting direct pathologist-to-patient interactions have appeared sporadically in the literature. Currently, some patients seek out other trusted physicians for help in delineating, and deciding on, their health-care choices. In one study, women with breast cancer often consulted their primary care provider on a specialist’s diagnoses and treatment recommendations. By participating in such discussions, pathologists could contribute valuable information to the patient about their laboratory reports, their diagnoses, how they were made, and the pathologist’s level of certainty in the diagnoses rendered. Potentially, knowing that information could help patients feel more confident accepting, and adhering to, their team’s treatment recommendations.

Recently, pilot pathologist-to-patient interventions have been described. With respect to the question of sharing laboratory reports directly with patients, in studying patients’ personal understanding of their surgical pathology reports, Mossanen et al showed that “pathology reports are written at reading levels above the average reading capability of most Americans.” They found that “deleting descriptive pathologic terms and replacing complex medical terminology with lay terms resulted in improved readability for some urologic oncology reports but complicated the readability for others.” Another report by the same group was aimed at reworking urinary bladder surgical pathology reports so that patients could better understand them. The result was a significant improvement in patients’ ability to identify the stage and grade of their cancer and understand the clinical implications.

Having personally observed the benefits of direct pathologist-to-patient communication in his own busy surgical pathology practice, Juan Rosai, MD, a leader in the surgical pathology field, organized an international meeting of pathology thought leaders at the lakeside resort community of Sirmione, in Northern Italy, from May 2 to 4, 2008 (Figure 1 and Table 1). The challenge from the sponsoring organization, Milestone Medical Technologies, a laboratory equipment company headquartered in nearby Bergamo, Italy, was to “identify and address a major surgical pathology issue.” At the opening session, the attendees agreed that direct communication between patients and pathologists was a serious need. An outgrowth of the “Sirmione Group” meeting was the creation of an online patient resource, by Jonathan I. Epstein, MD, at Johns Hopkins Medical School in Baltimore, a member of the

Figure 1. Organizational meeting of the “Sirmione Group,” at the lakeside resort city of Sirmione, in Northern Italy. Left to right: M. Sobrinho-Simões, MD; J. Rosai, MD (chair); R. J. Kurman, MD; F. Visinoni, Milestone Medical Inc., Bergamo, Italy (corporate sponsor); M. Dietel, MD; E. A. Montgomery, MD; R. S. Weinstein, MD; and J. I. Epstein, MD (see Table 1).
Table 1. Invitees at the Sirmione Group Meeting, May 2 to 4, 2008.

| Member | Institution | City/State/Country |
|--------|-------------|--------------------|
| Juan Rosai, MD (Chair) | Centro Diagnostico Italiano | Milan, Italy |
| Manfred Dietel, MD | Institute of Pathology | Berlin, Germany |
| Charité Humboldt University of Medicine | | |
| Jonathan I. Epstein, MD | The Johns Hopkins Medical Institutions | Baltimore, Maryland |
| Robert J. Kurman, MD | The Johns Hopkins Medical Institutions | Baltimore, Maryland |
| Elizabeth A. Montgomery, MD | The Johns Hopkins Medical Institutions | Baltimore, Maryland |
| Manuel Sobrinho-Simões, MD | University of Porto | Porto, Portugal |
| Ronald S. Weinstein, MD | The University of Arizona | Tucson, Arizona |
| Franco Visinoni (ad hoc member) | Milestone Medical Technologies | Bergamo, Italy |

The Sirmione Group.* Meeting in Sirmione, Italy.

Table 2. Pathologist-to-Patient Action Items to Enhance Access to Pathologist Expertise.

| Activity | References |
|----------|------------|
| A. Identify a need* | 17,18 |
| B. Create ACS “online/FAQ” website* | 17,18 |
| C. Examine pathologist–surgeon–oncologist communication* | 4,8 |
| D. Explore pathologist–patient engagement and solutions* | 10,11 |
| Concept 1. Pathology Explanation Clinic | 10,11,13,14 |
| Concept 2. Certified Pathology Navigator (CPN) | - |
| E. CPN training and certification programs* | - |
| F. Pilot program implementations | 30,31 |
| G. Validate with patient-centered outcomes research | 28,29 |
| H. Billing code reform* | 24,25,26 |

Abbreviations: ACS, American Cancer Society; FAQ, frequently asked questions.
*The Sirmione Group.
Provisional:
1 The University of Arizona College of Medicine-Tucson.
2 Appendix B: Funding for patient-centered outcomes research.
3 Appendix A: Pathologist payment models.

Sirmione Group. With the encouragement of the Sirmione Group, Epstein created a website entitled, “The FAQ (Frequently Asked Question) Initiative: Understanding Your Surgical Pathology Report.” The FAQs were developed by the Association of Directors of Anatomic and Surgical Pathology and have been endorsed by the College of American Pathologists. This Internet site is still active. It is maintained by the American Cancer Society as a public service for patients with cancer and their caregivers.18

Recently, The University of Arizona College of Medicine’s Department of Pathology followed up on the original Sirmione Group initiative, with the objective of further expediting direct pathologist-to-patient communication and increasing patient access to pathologist expertise. The Arizona group, inspired by the work of the Sirmione Group, but proceeding independently, compiled the set of “pathologist-to-patient” action items outlined in this concept paper (Table 2). Our intent is to seek input from, and partnerships with, pathology professional organizations, with the hope that the concept of a PEC can be validated through patient-centered outcomes research and then taken to scale in health-care delivery systems. Attention should also be given to advocating for specific pathologist-to-patient communication intervention billing codes (see Appendix B).

Communicating the Results of Surgical Pathology Reports to Patients

The communication of laboratory results directly to patients by experts will have its share of challenges, even in the new patient-centered care environment. In order to facilitate this level of pathologist-to-patient communication, we propose creating a specific category of specially trained laboratory test results-communicators, the so-called “Certified Pathologist Navigators (CPNs)” (see below). Clearly, not all pathologists would be interested in interacting directly with patients, nor would clinicians necessarily wish to share such responsibilities with pathologists. Those pathologists who are interested in being CPNs could opt into such programs and then train for the certification.

We envision that creation of this niche opportunity would include special training, extensive marketing of the concept on the part of organized pathology, and the proactive addressing of legal and regulatory issues that might emerge along the way. As for the participating pathologists, the training would be in such areas as interpersonal communication, cultural sensitivity, clinical medicine, standard and advanced therapeutics, statistics, precision medicine, population health, medical economics, and methodology for assessing patient health literacy.

Creation of Pathology Explanation Clinics

We propose that this practice model be called the “PEC.” For purposes of this introductory concept paper, we shall focus the discussion on how the PEC could be used for discussing a surgical pathology report with a patient, recognizing that this is one of a list of potential clinical applications. Another might be the discussion of results of genomic testing. In the surgical pathology example, a patient with a previous biopsy and its surgical pathology report would be provided with a handout, or the hyperlink to a website, that describes the PEC program. It offers instructions for an appointment at either a virtual PEC or a physical PEC location. The handout would explain the potential benefits and limitations of communicating directly with a pathologist. Alternatively, patients could learn about the
PEC from an oncologist, oncologic surgeon, or their primary care provider or by word of mouth from a friend or family member. Initially, the PEC might be held one day a week, as are many subspecialty clinics in academic medical centers. For a PEC held at an academic medical center, glass histopathology slides or whole-slide images (WSI) would be retrieved for the pathology resident on service to examine, much as is done for tumor board conferences. For PEC sessions held at teaching hospitals, a resident pathologist linked into sessions using bidirectional video conferencing. Video-enabled community tumor boards have been reported. In another version of a PEC clinic, the subspecialty pathologist CPN would be embedded into on-site clinics (ie, oncology clinics) during regular clinic hours. For example, at the head and neck oncology clinic held weekly at many academic medical centers, the subspecialty head and neck pathologist would be present at the clinic and see patients immediately after their pathology reports are provided to patients by their clinicians. This practice model eliminates the need for a separate PEC appointment, but it does not give patients time to adjust to their new diagnosis. The attendance of patients at the PEC appointment could be done virtually, with the patient, and the pathologist linked into sessions using bidirectional video conferencing. Video-enabled community tumor boards have been reported.

### Training Certified Pathology Navigators

At the Department of Pathology at The University of Arizona College of Medicine–Tucson, we are developing a training program for this new category of health worker, the “CPN.” These CPNs will have special competencies for communicating directly with patients, regarding the interpretations and implications of their pathology reports. Initially, the CPNs would be boarded pathologists with additional training, through a certificate program, on communicating directly with patients. For purposes of creating the initial certificate program for the CPNs, we are assuming that the initial targeted interaction between a patient and the CPN will take place after the patient’s primary care physician, oncologist, or surgeon has informed the patient of the results of their surgical pathology biopsy report. This timing is in deference to some patients’ preferences for receiving “bad news” face-to-face with a physician or nurse in a physician’s office, with no additional health professionals in the room.

We are in the process of developing the initial scripts, and visuals, to be followed and described by the CPNs during their appointments with the newly diagnosed patients with cancer.

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Figure 2. Atlas of medical images for both patients’ supervised, or independent, study. Histopathology of benign and malignant human tissue. Upper left: Benign breast tissue in a 75-year-old woman. Upper right: Breast cancer. Lower left: Prostate gland, benign prostatic hyperplasia. Lower right: Adenocarcinoma of the prostate gland. Hematoxylin and eosin staining. ×20 magnification. Whole-slide images (WSI).
other health-care providers. In fact, it is reasonable to expect
opinion requests, have predominantly been conducted with
customary for pathologists to interact directly with patients.
Nevertheless, this could be somewhat challenging as it is not
health literacy, could lend added legitimacy to the service.
A pathologist–patient education consultation, if tied to patient
advocacy at the Centers for Medicare/Medicaid Services level.

One option would be to initiate a new CPT code for patholo-
nications interventions. A cash payment model would allow
pathologists to directly bill patients for their patient consulta-
tions. This model is currently used when patients request a second opinion and insurance companies do not cover
the service. Ultimately, it is incumbent on pathologists to
demonstrate that patient counseling improves clinical care and
patient outcomes in some meaningful way to justify
reimbursement.

Potential Sources of Funding for Patient-Centered
Outcome Research
Development and implementation of the PEC model would of
course require a significant amount of fundamental research
and work to validate its utility and impact on patient care and
outcomes. Efforts to involve patients more in their own care, to increase health literacy, and improve patient outcomes by tailoring medicine to the individual are increasingly being funded by federal (eg, National Institutes of Health, Agency for Healthcare Research and Quality, Department of Defense Medical Research and Materiel Command) and other grant agencies. In particular, the Patient-Centered Outcomes Research Institute (PCORI) is a relatively new, nonprofit, nongovernmental organization in Washington, DC. Funding for the PCORI was authorized by the US Congress in 2010.\(^{27,28}\) It could potentially be tapped for clinical research projects related to the “Patient-Centered Diagnostic Pathology” concept. The PCORI’s mandate is to improve the quality and relevance of information available to help patients, caregivers, insurers, and policy makers render better informed health-care decisions. Focusing the adequacy and suitability of communication at the patient-to-pathologist interface might fall within the PCORI mission. We can envision how funding from any of these agencies might be applicable to the study of issues regarding best practices in helping patients understand the content and ramifications of their laboratory reports. The University of Arizona Department of Pathology, which houses the state-wide multispecialty Arizona Telemedicine Program, has been partially supported by a PCORI grant which funds a study on the use of telehealth to instruct colostomy and urostomy patients on the management of their ostomies.\(^{29}\)

**Authors’ Note**

The Sirmione Group Meeting, May 2 to 4, 2008, was sponsored by Milestone Medical Inc., a laboratory equipment company headquartered in Bergamo, Italy. The company president, Franco Visinoni, participated in the initial session and the closing session of this 5-day meeting.

**Declaration of Conflicting Interests**

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