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Ethics in Pathology

From the Editor

- Ethical Considerations in Pathology** 761
Margaret Cocks

Ethics Cases

- Ethical Questions about Platelet Transfusions at the End of Life** 764
Commentary by John P. Sherbeck and Renee D. Boss

- Is Consent to Autopsy Necessary? Cartesian Dualism in Medicine and Its Limitations** 771
Commentary by Megan Lane and Christian J. Vercler

- I Might Have Some Bad News: Disclosing Preliminary Pathology Results** 779
Commentary by Michael H. Roh and Andrew G. Shuman

- Requests for VIP Treatment in Pathology: Implications for Social Justice and Systems-Based Practice** 786
Commentary by Virginia Sheffield and Lauren B. Smith

- Ordering Stains That Aren't Indicated** 793
Commentary by Martin J. Magers and Sandro K. Cinti

Podcast

- Clinical and Research Ethics in Pathology: An Interview with Theonia Boyd**

The Code Says

- The AMA Code of Medical Ethics' Opinions Applicable to Pathology** 800
Danielle Hahn Chaet

Medical Education

- Improving Pathologists' Communication Skills** 802
Suzanne Dintzis

In the Literature

- Error Disclosure in Pathology and Laboratory Medicine: A Review of the Literature** 809
Ifeoma U. Perkins

State of the Art and Science

- Pathology Image-Sharing on Social Media: Recommendations for Protecting Privacy While Motivating Education** 817
Genevieve M. Crane and Jerad M. Gardner

Policy Forum

- Ethical Considerations about EHR-Mediated Results Disclosure and Pathology Information Presented via Patient Portals** 826
Kristina A. Davis and Lauren B. Smith

Medicine and Society

- The Penetrating Gaze and the Decline of the Autopsy** 833
William E. Stempsey
- Public Figures, Professional Ethics, and the Media** 839
David R. Fowler

Images of Healing and Learning

- The Use of Visual Arts as a Window to Diagnosing Medical Pathologies** 843
Katrina A. Bramstedt

About the Contributors 855

FROM THE EDITOR

Ethical Considerations in Pathology

Pathology, as a medical specialty, deals with the interpretation of changes in human tissues that cause or are caused by disease. Pathologists render diagnoses from laboratory analyses of varied specimens such as blood, urine, and other body fluids as well as microscopic examination of solid tissue from biopsies or surgical resections. In addition to diagnosis, pathologists determine cause and effect of death and disease through autopsy and techniques of molecular pathology. Pathologists are thus laboratory-based physicians. In medicine, they are sometimes stereotyped as basement dwellers, removed from direct patient contact, working with only the dead and inert. On this stereotype of pathologists as sheltered in their subterranean quarters, issues of medical ethics might seem a distant consideration.

There are good reasons, however, to carefully consider pathology ethics. A survey of American pathology department chairs across the United States found that 94 percent believed ethical issues were faced by pathologists either occasionally or frequently [1]. Commonly encountered ethical scenarios involved use of tissues for research, professionalism, and confidentiality or privacy [1]. Additionally, “84 percent of [representatives of residency] programs believed that ethical issues were underrecognized, and 38 percent believed that current ethics training was inadequate” [2], although 62 percent reported offering formal ethics instruction in residency training programs. A more recent international survey of ethics training in laboratory medicine found that even fewer programs offered formal training in ethics: roughly a third of surveyed programs offered formal training in medical ethics and roughly a quarter offered formal training in professional ethics [3]. Clearly, there is a need for better training in pathology ethics and more resources to address the often unique ethical scenarios encountered by pathologists in medicine.

A goal of this issue of the *AMA Journal of Ethics*® is to bring to light some of the ethical complexities faced by pathologists in their daily practice. The five cases presented here explore a few common scenarios and offer practical guidance for navigating them. In their commentary on a case of [consent for autopsy](#), Megan Lane and Christian J. Vercler argue that a sociocultural—but not a Cartesian—perspective on the postmortem body necessitates informed consent and discuss how to approach a family about consent when the autopsy’s purpose is to investigate possible surgical error. Two cases look at professional interactions between the pathologist and clinician. In their commentary on a case involving preferential [treatment of a VIP patient](#), Virginia Sheffield and Lauren B.

Smith examine possible harms of this practice and institutional factors contributing to it. Martin J. Magers and Sandro K. Cinti respond to a case of a clinician's request for additional [tissue stains that are not indicated](#) by recommending that pathologists not put professional relationships before the patient's best interest. Although direct patient interaction is limited in pathology, cytopathologists can be directly involved with patient care when they perform fine needle aspirations at a patient's bedside. Michael H. Roh and Andrew G. Shuman discuss an [obligation to disclose](#)—and barriers to disclosure—in a case involving a patient's request for disclosure of a preliminary diagnosis that would be “bad news.” The final case examines ethical obligations of pathologists in their roles as laboratory managers. John P. Sherbeck and Renee D. Boss examine the conflict between the ethical principles of beneficence and social justice in a case involving a decision about platelet [transfusion for a palliative care patient](#).

A central theme in this issue is communication—between physicians; among physicians, patients, and patients' loved ones; and even virtually, through social media. Two articles examine improving professional communication and obstacles to transparency. Suzanne Dintzis describes a course for pathology residents that she and her colleagues at the University of Washington developed to cultivate best practice procedures for [effective communication](#). And Ifeoma U. Perkins reviews the literature on and discusses four barriers to pathologists' [disclosure of medical errors](#).

New technologies that enable rapid sharing of information generate ethical questions, both familiar and novel. The visual and aesthetic nature of pathology makes it especially easy to use social media platforms, such as Twitter and Instagram, to share images and information, but doing so raises concerns about potential privacy violations. But as Genevieve M. Crane and Jerad M. Gardner argue, social media posts should be governed by the same ethical standards as images published in a case report, and the authors present [ethical and practical guidelines](#) for pathologists who use social media professionally. New ethical concerns have also arisen with the evolution of direct-to-patient laboratory test reporting, which enables patients to access lab results without physician interpretation. Kristina A. Davis and Lauren B. Smith evaluate some of the risks and benefits of the ease with which patients can access basic laboratory information and specialized pathology reports through [online patient portals](#).

Observation is another central theme of this issue. William E. Stempsey develops Foucault's concept of “the gaze” to explore differences between pathologists' and families' [perceptions of autopsy](#) with a view to improving informed consent, which, in turn, should lead to more—and more carefully considered—autopsies. And Katrina A. Bramstedt discusses the [training in visual arts](#) afforded by Bond University's medical humanities program and students' positive assessment of the curriculum.

Finally, in this issue's podcast, Theonia Boyd discusses clinical and ethical reasons for completing an autopsy as well as a few of the ethical issues faced by pathologists in their role as [medical expert witness](#).

The advent of new technologies and the rise of molecular pathology promise to bring even more complex ethical questions to the fore. The selection of case commentaries and articles in this issue of the *AMA Journal of Ethics* gets us thinking about ethical issues by addressing a few neglected ethical questions that are nonetheless common in pathology and laboratory medicine.

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ETHICS CASE

Ethical Questions about Platelet Transfusions at the End of Life

Commentary by John P. Sherbeck, MD, and Renee D. Boss, MD

Abstract

This case of platelet transfusion in palliative care illustrates a common dilemma in transfusion medicine: approval of the use of a scarce, yet potentially life-saving, resource. As in this case, these decisions often involve seriously ill patients with acute needs and evolving goals of care. The use of resources to treat the patient at hand must be balanced against maintaining adequate resources to treat future patients. In this setting, the ethical principles of beneficence and social justice are in conflict.

Case

Dr. J, a second-year resident on the palliative care service, has become quite close to his patient, Emma, a 5-year-old girl with acute lymphoblastic leukemia. Two years ago, Emma completed successful chemotherapy and achieved remission, but a recent bone marrow biopsy showed lymphoblastic infiltration. She was started on a rescue therapy program with little response and underwent a bone marrow transplant. During this relapse, she has been hospitalized on multiple occasions for infections and bleeding, which required blood and platelet transfusions, and is now receiving palliative care for tumor lysis syndrome. It is Emma's medical team's opinion that there is no more that can be done to cure her leukemia, which prompted her transfer to the palliative care service. Shortly after transfer, Emma developed bright red blood per rectum, and Dr. J requested human leukocyte antigen (HLA)-matched platelet transfusion for her to help stop the bleeding.

Dr. S, a third-year pathology resident, received Dr. J's request for HLA-matched platelets. Typically, pathologists oversee platelet distribution, since they are the physicians responsible for administering transfusion services in a hospital—maintaining an adequate blood supply, monitoring blood donor and patient-recipient safety, ensuring appropriate blood utilization, and directing the preparation and safe use of blood components according to a hospital's platelet distribution protocol. Since Dr. S oversees a busy transfusion service with many sick patients requiring blood and platelets, one of her duties is to carefully assess each request for these limited resources. She contacts Dr. J and asks for more information about his request. Dr. S explains that HLA-matched

platelets are in short supply and most often used for patients who are still being aggressively treated to try to cure their illness.

Dr. J responds, “Hmmm. . . . Why would the fact that a patient is no longer receiving aggressive acute care prompt us to reconsider her use of this resource? We still have an obligation to treat her, even when the goal is palliative rather than curative.” Both physicians wonder about how to proceed.

Commentary

Platelet Transfusion Basics

Like most products under the umbrella of transfusion medicine, platelet transfusions are derived from human donors. Platelets can be derived from a single donor (apheresis unit) or from multiple whole blood donors (pooled unit). In all cases of matched or directed donations, the product is an apheresis unit.

Clinical indications for platelet transfusion. Patients with indications for platelet transfusion generally fall into two categories: those with thrombocytopenia with active bleeding or nonbleeding patients at imminent risk of bleeding, for whom transfusion is used prophylactically. The latter include nonbleeding patients with severe thrombocytopenia (i.e., less than 10,000 platelets per microliter of blood) and patients with ongoing bone marrow suppression due to active chemotherapy or infection, for example. Thresholds for prophylactic platelet transfusion have been well studied [1]. One important consideration is the duration of the treatment effect; unlike red cell transfusion, in which a nonbleeding patient can experience benefit for weeks, the short life cycle of a platelet *in vivo* limits the therapeutic benefit to hours or days. Therefore, a single chronically thrombocytopenic patient, like Emma, might require an extraordinary number of transfusions over time.

Alloimmunization. If the transfused platelets harbor antigens that the recipient’s immune system views as foreign, immune sensitization (alloimmunization) can occur. Human leukocyte antigen (HLA) class I antigens are by far the most common cause of platelet alloimmunization [2]. Subsequent transfusions harboring that antigen can result in antibody-mediated destruction of the donor platelets, a phenomenon known as premature clearance. Failure of the transfusion to raise platelet counts due to premature clearance of the platelets is clinically referred to as *refractoriness*. (It is worth noting, however, that not all cases of platelet refractoriness are immune mediated.) Platelet refractoriness is typically defined as three consecutive transfusions with less than expected (based on platelet dose and estimated body surface area) rise in platelet counts at one-hour post transfusion [3]. Not surprisingly, the theoretical risk of alloimmunization rises with the number of transfusions (both packed red cells and

platelets). However, even with repeated exposure, alloimmunization—and resulting refractoriness—occurs in a minority of patients [2, 4, 5].

Compatibility and scarcity of donors for HLA platelets. As alluded to in the case, and as mentioned above, platelets harbor HLA class I antigens, which are a common target for immune sensitization. To combat immune refractoriness, patients can receive platelets from specific donors with HLA-compatible antigens (“HLA platelets”). Testing for compatibility is performed *in vitro* and evaluates both the patient’s own HLA antigens and the reactivity of the patient’s plasma against other class I antigens found in the general population. Blood products are either HLA-compatible (i.e., the recipient plasma does not harbor HLA antibodies that react to the HLA antigens on the donor platelets) or HLA-identical (i.e., the recipient and donor HLA antigens are identical) [3]. In patients for whom it is difficult to find HLA-compatible platelets, cross-matched platelets—those that do not react *in vitro* with the recipient’s serum irrespective of antigen or antibody status—can be a suitable alternative.

Ethically and Clinically Relevant Considerations for Platelet Allocation in Transfusion Medicine

Finding donors. While HLA platelets have potential to support chronically transfused, refractory patients, finding suitable donors can be a monumental task. Blood suppliers, including the American Red Cross, maintain national databases of known platelet donors and their HLA type and facilitate testing and identification [6]. Once a suitable donor is found, a number of time-sensitive criteria must be met. First and foremost, donors must be currently eligible to donate (according to Red Cross or other eligibility requirements). Second, the donated platelets must be expeditiously collected, processed, and shipped to the transfusion center, since platelet lifespan is typically five days after collection. The issue of cost is also paramount; blood products, in general, are one of the largest costs within a laboratory. The additional work to process HLA platelets drives the cost of an apheresis unit significantly higher than a random platelet unit [7]. Because of these criteria and cost considerations, random platelets should be transfused in the event of acute, life-threatening bleeding, even in patients who have historically received HLA platelets. In other words, in an urgent situation, the risk of immune refractoriness is tolerated, from an ethical and clinical standpoint, to respond robustly to the acuity of a patient’s condition.

Palliative care transfusions considerations. The World Health Organization (WHO) defines [palliative care](#) as “improving the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering” [8]. There is very little literature addressing practical or ethical considerations that arise in cases of bleeding due to thrombocytopenia in nontrauma patients near the end of life, however [9, 10]. Bleeding can create suffering for all involved; platelet transfusion would be a palliative intervention. During active bleeding,

the use of random platelets is warranted. If the patient is already immune refractory, pooled platelets may be superior to apheresis platelets, as there is a greater chance that at least one of the donors is compatible with the patient [11]. In general, transfusion practices for patients at the end of life are similar to those for the general population. Yet platelet transfusion in the seriously ill, which is common, is often an acute approach to a chronic problem. And because chronically transfused patients are at increasing risk of becoming alloimmunized, they can pose a large burden to the HLA platelet supply.

Regardless of the underlying pathology, transfusion is not a curative therapy but an acute treatment for a symptom of the underlying process. Therefore, patients without a goal of cure remain eligible for transfusion as a part of symptom management. Yet, unique questions arise when considering the use of the scarce resource of HLA platelets for patients near the end of life. The key benefit of HLA platelets is for refractory patients who need ongoing, long-term transfusion. It is reasonable to consider reserving HLA platelets for those patients with longer life expectancies. Diverting HLA platelets to a patient who will not receive the long-term benefit is potentially diverting them away from a patient who will. Alternative strategies do exist for bleeding patients like Emma, including the use of random platelets, local hemorrhage control, and so on. The preemptive use of HLA platelets as a prophylactic against alloimmunization should not be attempted; it creates an undue burden on the population and causes a delay in platelet delivery and associated symptom relief [12, 13].

HLA platelet distribution policies. While caring for the individual patient is the goal at the bedside, organizations must balance individual goals of care with the capacity to care for *all* patients. This is the essence of the ethical conflict between beneficence and social justice. The use of scarce HLA platelets is a prime example of the difficulty in balancing the needs of the individual with the needs of the population. While there is no substitute for clinical decision making, organizations must establish policies that ensure rational and [just use of limited resources](#). A platelet distribution protocol is an example of an organizational policy to reduce unnecessary variability in transfusion practices and, in so doing, increase availability of blood products for all patients [14, 15]. It is important to note that platelet distribution protocols generally target objective platelet levels or degree of hemostasis without consideration of subjective patient comfort or distress. The protocols can thus create a bias in favor of acute over palliative goals of care. In situations in which patient or family requests for transfusion conflict with clinician recommendations, ethics consultations should be considered.

When facing decisions about more critical resource shortages, like HLA platelets, organizations often require involvement of expert consultants or gatekeepers, like Dr. S in this case. Typically, these are blood bank medical directors or pathology residents or fellows acting in their stead. The purpose of the consultant is to act as a liaison between the laboratory and the wards and act as a careful steward of resources. The pathologist

performs a laboratory evaluation to address a series of clinical and empirical questions: Is the patient platelet refractory? If so, what is the likelihood the patient is alloimmunized? Once these questions are answered, appropriate transfusion recommendations can be made. The pathologist's role is, first and foremost, to ensure that patients who need blood products have access to them. But appropriate use is a moving target. Releasing a platelet unit for a patient with a count of less than 50 platelets per microliter of blood prior to a diagnostic lumbar puncture is appropriate when there is plenty of product. If the same request is made at a trauma center with a severe platelet shortage, it would be reasonable to deny the request until inventory has improved. To return to Emma's case, because she is actively bleeding, she should receive random platelets and be monitored for evidence of refractoriness.

Communication between pathologists and clinicians. Throughout this consultative process it is imperative that lines of communication remain open. A pathologist is typically unable to assess the patient at the bedside and thus relies on clinical colleagues to paint a timely and accurate picture of the patient's condition, vulnerabilities, and needs. Likewise, it is imperative that the blood bank or the pathologist communicates to clinicians about inventory and product selection relevant to the patient. This communication allows for appropriate triaging and use of products, such as HLA platelets, in times of shortage. Although usage of the word "gatekeeper" might imply an adversarial relationship for some, a common goal of both the bedside clinician and the pathologist is to appropriately manage the patient.

Application to the Case

For Emma, whose active bleeding is likely due in some part to thrombocytopenia, it is appropriate to initiate a platelet transfusion now to limit her distress and increase her comfort. Given the inherent time delay for HLA platelets, together with the lack of evidence that she is immune refractory, she should be transfused with random platelets. Additional methods to control hemorrhage, including localized pressure, should be used as well. Once Emma is transfused, her platelet counts should be closely monitored, and if her thrombocytopenia remains refractory to platelet transfusion, she should be further evaluated for possible alloimmunization. Early discussions with Emma's physicians, her family, and both blood bank and ethics consultants could assist with coordinating goals of care if HLA platelets are indicated to improve Emma's comfort.

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Related in the *AMA Journal of Ethics*

[Improving Health Outcomes and Promoting Stewardship of Resources: ABIM Foundation's Choosing Wisely Campaign](#), November 2012

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

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ETHICS CASE

Is Consent to Autopsy Necessary? Cartesian Dualism in Medicine and Its Limitations

Commentary by Megan Lane and Christian J. Vercler, MD, MA

Abstract

When a hospitalization ends in death, a request for an autopsy can lead to an emotionally charged encounter between a physician and the deceased patient's family. A case is presented in which a cardiac surgeon, believing he might have made a mistake, requests an autopsy, but members of the deceased patient's family believe that she would not have wanted an autopsy performed. A central question discussed in this commentary is whether and when consent for autopsy is necessary. We discuss two theoretical frameworks that support differing views on this question. Beyond engaging this philosophical discussion, we also highlight a practical approach to discussing an autopsy with a grieving family by using the case presented.

Case

Dr. Zinker, a cardiac surgeon, is surprised by the rapid and unexpected death of his patient, Ms. Foster, whose postsurgery recovery had appeared complication-free. Prior to her death, she complained of shortness of breath and was found to have a pleural effusion, an abnormal volume of fluid around one of her lungs. The pleural effusion was drained, but she developed unstable blood pressure, which required increasing administration of vasopressors. Despite these supports, Ms. Foster died. Dr. Zinker wants to order an autopsy to determine the exact cause of Ms. Foster's death. Specifically, he wants to discover whether something he did during the surgery contributed to her unexpected death.

Dr. Zinker meets with Ms. Foster's husband, Jim, and adult daughter, Alta, to obtain consent for an autopsy. He explains to them what's involved in an autopsy and how long it might take. The normal protocol for autopsy includes examining both the head and the body, but Dr. Zinker explains that the family may limit autopsy to the body if so desired. He also explains that the autopsy should take a few hours and that preliminary results would be available shortly after the procedure was complete. He tells the family that final results might not be available for several weeks because academic autopsies often involve microscopic evaluation of tissues, which requires additional histologic processing. Jim and Alta are reluctant to consent to the autopsy of Ms. Foster, stating, "She's already

suffered so much. I can't imagine putting her body through that." They are also concerned about delaying her funeral. Finally, they ask, "Why do you want to do an autopsy, anyway? Why does it matter now?"

Dr. Zinker wonders what to say next. Is understanding what happened to Ms. Foster worth further upsetting her grieving family? How should he counsel them about the autopsy process? Should he admit that there might have been a surgical error? He contacts the hospital's pathologist for advice.

Commentary

This case illuminates concerns about postmortem care and communication revolving around a central question: For whom do we perform autopsies? Is the act of determining cause of death for the benefit of the deceased, his or her family, a physician, or future patients? The autopsy is a unique medical procedure from which a deceased patient does not benefit, yet the information gleaned from it can provide closure for a grieving family, data for quality improvement, or evidence for criminal prosecution.

In the case, Dr. Zinker wants to ask a pathologist to perform an autopsy to learn from his possible mistakes and to improve his practice. Autopsies continue to play a critical role in [improving patient care](#) and diagnostic ability. A 2003 meta-analysis found that the median error rate for clinically undiagnosed conditions "involving a principal underlying disease or primary cause of death" was 23.5 percent [1]. The autopsy is a powerful tool for student learning as well as improvement in care. For example, the Accreditation Council for Graduate Medical Education requires residents in anatomic and clinical pathology to perform at least 50 autopsies and to review autopsy reports with a faculty member [2]. Although the autopsy is a critical component of medical education and clinical development, performing autopsies can conflict with the wishes of stakeholders.

Living individuals—for example, family members, physicians, criminal investigators—have competing interests in the dead. To determine whether consent for autopsy is ethically required in this case, it is necessary to discuss the status of Ms. Foster's body after death. Should her remains be considered a deceased patient who is entitled to the respect expressed toward the living or an inanimate *object* that physicians and interested parties can act upon at will? Or, is there a kind of middle ground that should be considered? In our pluralistic society, settling a larger metaphysical question of what happens to the self or identity after death is impossible. Hence we will examine the general Cartesian view of the body after death that pervades contemporary clinical practice and then take a clinical sociocultural approach in an effort to respect multiple interpretations of the quiddity of a corpse. We will argue that a plurality of beliefs about the body after death call for consent to autopsy in most circumstances. We then consider how physicians might approach families of deceased patients to request an autopsy in light of this perspective.

A Cartesian Perspective on the Postmortem Body and Its Limitations

Cartesian dualism. Cartesian dualism, born of sixteenth-century rationalist philosophy, provides a framework in which Ms. Foster's death would completely separate her body from her mind and past identity. René Descartes's *cogito ergo sum* ("I think, therefore I am") posits the existence of the self in the (immaterial) mind as opposed to in the (material) body [3]. According to this view, in death, thinking stops, and so the body is separated from the mind and the thinking, reflective "I" no longer exists there. In death, the body becomes an *object*, and the *person* is no longer embodied: "even if there were no body, the soul [mind] would not cease to be all that it is" [4]. Dualism permeates discussions of death in the medical community; specifically, this principle provides a basic philosophical underpinning of medical definitions of death. Harvard Medical School's 1968 "Definition of Irreversible Coma" defines as a "new criterion of death" irreversible coma, in which "individuals ... have no discernible central nervous system activity" [5]. The 1981 *Defining Death* report [6] provides two definitions of death pivoting around the function of the brain: the "higher brain" definition, which defines death as a cessation of higher cortical functions that make "consciousness, thought, and feeling possible" [7] and the "whole brain" definition, which posits the brain as the primary regulator or the "integrated functioning of brain, heart and lung" [8]. Concluding that the "higher brain" "may well exist only as a metaphorical concept" [9], the report espoused "whole brain" formulations in its proposed Uniform Determination of Death Act, which the authors claimed "does not appear to conflict with the view that the soul leaves the body at death" [10]. With the [death of the brain](#), does the body become an object, on a Cartesian view?

Whatever the answer to this question, Cartesian dualism influences medical definitions of death and can also influence a practitioner's view of the postmortem patient. If the dead body is an object, we would not expect this object to have any independent wishes, thoughts, or desires, and, presumably, there would be no autonomy to respect within a consent process. If Ms. Foster's dead body is an object, one could argue that Dr. Zinker would not need consent for an autopsy of her body.

Limitations to dualism. Although Cartesian dualism is consistent with some rationalist underpinnings of the practice of medicine, such as the medical determination of death, a Cartesian perspective on the dead body as object ignores a complex plurality of cultural and social perspectives on the body after one is deceased. John Drayton, in "Bodies-in-Life/Bodies-in-Death," suggests that the objective use of the body dictated by dualism is complicated by bereavement, or "our memories of others...based on behaviour associated with their bodies" [11]. D. Gareth Jones, author of *Speaking for the Dead: Cadavers in Biology and Medicine*, also points to this idea:

When we turn to a cadaver's *instrumental value*, we recognize that it serves as a vital source of memories and responses.... As we remember a person who has died, we respect the person who *was*. All that remains of the person is the cadaver, and yet our respect for that person, and for the memory of that person, leads to respect for the person's remains, a link that is not readily broken [12].

Both Drayton and Jones suggest that a person's body holds unique value beyond that of a lifeless object. This worth is constructed through others' memories of and respect for the deceased person, and it is exercised in a broad range of social, cultural, and [spiritual traditions](#) surrounding disposal of the dead. Drayton and Jones's emphasis on the continued value of the deceased's identity in relation to the deceased's body highlights the clinical and ethical importance of consent for autopsy and complicates clinical understandings of death influenced by dualism.

Respect for Sociocultural Traditions and Consent

Respecting sociocultural differences. Given the value of the body after death expressed by thinkers like Drayton and Jones and that a deceased person's wishes can be preserved through living relatives, it follows that family members' consent should be taken into consideration to proceed to an autopsy. As an extension of family members' connections to the patient, the patient's perceived desires, wishes, and sociocultural beliefs should be incorporated into the family's decision about whether to perform an autopsy, analogous to [surrogate decision making](#), in which next-of-kin must rely on an incapacitated patient's past attitudes, actions, and values to make health care decisions. Like clinical decisions, the consent process and autopsy can be adjusted to accommodate the sociocultural beliefs of an individual and his or her family while gaining the information that can prompt a clinician's request for the procedure.

An example of this conceptual accommodation occurs in the cooperation between New Zealand forensic pathologists and Māori patients and family members. Māori cultural beliefs about death and the body conflict with allopathic forensic practices of organ retention and biomaterial destruction, but accommodations can and have been made to honor Māori beliefs [13]. This approach acknowledges that the value of a dead human body can transcend that of an object, and that the dead person's identity can be preserved and respected through family members.

The clinician should discuss the patient's and family's views and values in [a consent process](#) to autopsy, similar to all other aspects of clinical care of the patient. In the case presented, it would fall to Dr. Zinker to obtain consent from Ms. Foster's husband and daughter and try to understand their sociocultural background to best accommodate Ms. Foster's perceived wishes. By taking a sociocultural approach, the physician can try to honor the autonomy of the deceased person by allowing the next-of-kin to communicate

their perceptions of that person's wishes and desires and by respecting the deceased's spiritual and cultural perceptions of death.

An exception to this approach. There are some circumstances in which consent to autopsy is not required, most notably in forensic cases when information from an autopsy might lead to prosecuting or convicting someone who caused harm to the deceased. This exception is understood to be a compromise that expresses respect for individual autonomy and motivates collective justice. Information from an autopsy can be used to gain information about a crime and prevent such crimes from occurring to others in the future. In the case presented, if Dr. Zinker believed that a mistake he made would be systematic and that more of his patients could be at risk of dying under similar circumstances, the protection of others in the future could justifiably override respect for autonomy. If Dr. Zinker's mistake occurred out of negligence and could be reproduced in the future, the protection of others could also override deference to Ms. Foster or her family's beliefs. Neither scenario seems to be applicable in this case, however.

An Approach to Consent for Autopsy

The benefits gained by performing an autopsy are not so great as to immediately trump potentially competing values held by a deceased patient's family members. In a forensic case the need to pursue justice, as expressed in long-standing legal precedent, overrides even family members' objections to autopsy. Approaching a family for autopsy consent after a loved one has died (regardless of the cause of death) is nearly always difficult. In addition to concerns about suffering (suggested in the case above by the response Ms. Foster's family gave Dr. Zinker), lack of information about why an autopsy might be needed and the steps of the procedure itself have been identified as leading reasons for autopsy refusal [14]. In our case, Dr. Zinker should clarify why he is suggesting the procedure, communicating to the family that he wants to determine whether something he did during Ms. Foster's surgery could have contributed to her death. [Error disclosure](#) is now a well-established practice in medicine, and the Michigan model disclosure method has been shown to reduce legal claims and liability costs [15]. In following the Michigan model, Dr. Zinker should "reach out to those harmed, be honest, explain where appropriate, disclose [his] mistakes, and learn from [his] experiences" [16]. By explaining that he might have done something during surgery that contributed to Ms. Foster's death and that an autopsy could bring that to light and prevent it from being repeated, Dr. Zinker could better communicate clearly and honestly with Ms. Foster's family. He might say, for example:

I was surprised and saddened by Ms. Foster's death. I have to tell you that I thought her surgery went very well, and it is shocking to me that she died so suddenly and unexpectedly. I know she has been through a lot, and this seems like putting her through even more—but I would like to know whether anything I did contributed to her unexpected death. If so, I want to know, so

that I can apologize to you and so that we can work to prevent outcomes like this—if, indeed, they are preventable—in the future.

Dr. Zinker could also employ the aid of a [bereavement counselor](#) when communicating this message. A bereavement counselor is a specialist in the grieving process who could potentially aid Dr. Zinker in communicating effectively with her family. An audit of the necropsy rate in one hospital department in the United Kingdom found that the patient affairs officer was 18 percent more successful in securing consent for autopsies than junior physicians [17]. The authors speculate that the patient affairs officer had a higher comfort level in requesting autopsies and better communication skills than the junior physicians [17]. If Ms. Foster's family continues to refuse the autopsy after a clear explanation of its perceived need, this refusal should be honored, as would be expected were a living patient to refuse a procedure.

Conclusion

The term "autopsy" comes from the Greek term *autopsia*, meaning "a seeing with one's own eyes" [18]. We tend to project our own varied perspectives of death and our desires for knowledge onto the acts of requesting and consenting to an autopsy. In medicine, we are drawn to a Cartesian dualism to characterize death. There is the tendency to forget that a patient is still physically in the hospital after CPR has ceased or that a brain-dead patient might still be viewed as living to some family members. We live in a pluralistic society with many views and rituals of death, and imposing one view in which the body is an *object* that can be used for information without consent can potentially harm patients and families whose beliefs differ. In order to preserve autonomy and ensure beneficence, a discussion about the benefits and risks of autopsy with the family is paramount.

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ETHICS CASE

I Might Have Some Bad News: Disclosing Preliminary Pathology Results

Commentary by Michael H. Roh, MD, PhD, and Andrew G. Shuman, MD

Abstract

Cytopathology is a subspecialty of pathology in which pathologists frequently interact directly with patients. Often this interaction is in the context of fine needle aspiration (FNA) procedures performed at the bedside by the cytopathologist or by another clinician with the cytopathologist present. Patient requests for preliminary results in such settings raise fundamental questions about professional scope of practice and communication of uncertainty that apply not merely to pathologists but to all clinicians. In certain settings, cytopathologists may share preliminary diagnostic impressions directly with patients. Essential to these conversations is the need to articulate potential uncertainty about both the diagnosis and next steps. In addition, the involvement and notification of the referring physician is obligatory, both for care coordination and to ensure that patients receive a consistent message.

Case

Dr. H is a cytopathologist who performs and interprets fine needle aspirations (FNAs) of suspicious lesions, typically at a patient's bedside. Often, a radiologist obtains the sample with the help of radiologic image guidance, and the cytopathologist examines a portion of the sample in the form of Diff-Quik®-stained smears under a microscope during the rapid onsite evaluation (ROSE), used primarily to assess whether a sample is adequate. This procedure can offer the opportunity to disclose a preliminary diagnosis. The remainder of the sample is subsequently processed by the lab after the conclusion of the procedure. A diagnosis is not given until the sample is processed by the cytopathology laboratory and all the slides are evaluated under the microscope. If necessary, additional tests are ordered on this final sample prior to diagnosis.

One morning, Dr. H is attending his patient, Mr. Smith, a man with a history of melanoma who presented with a new soft tissue lesion in his abdomen. Mr. Smith's oncologist has consulted radiology for an ultrasound-guided FNA of the lesion, and Dr. H is on site as the attending pathologist to review the slides. As Dr. H is concluding his review of the Diff-Quik-stained smears, Mr. Smith says that he wants very badly to get his diagnosis today. Dr. H explains that the final report will not be released until all the slides are evaluated, probably the next day or the day after. "I know it's hard to wait," Dr. H says,

continuing, “Typically the lab processes the specimen so that I can better evaluate the cells under a microscope and order additional tests if necessary.” Mr. Smith seems exasperated at this and pleads, “Please, doctor, please tell me what you see. If it’s bad news, I’ll have my family around me tonight. If it’s good news, we’ll celebrate. I beg you to just tell me what you see.”

Looking at the Diff-Quik-stained smears from Mr. Smith’s sample under the microscope at his bedside, Dr. H sees cells that are clearly indicative of a malignancy. Nonetheless, he cannot definitively identify these cells as a metastatic melanoma or another primary cancer (e.g., metastatic carcinoma), and he wonders how to answer Mr. Smith.

Commentary

The scenario depicted above involving a cytopathologist—a subspecialist in pathology who frequently interacts directly with patients—is not uncommon. There is no single “right” answer to the question of how this specific situation, in which the patient pleads for a preliminary diagnosis from the cytopathologist, should be handled.

Mr. Smith’s request raises fundamental questions about professional [scope of practice](#) and communication of uncertainty that apply not merely to pathologists but to all clinicians. Many patients are aware that a pathologist is able to assess a specimen quickly and offer a preliminary diagnosis at the bedside. This is, indeed, the objective of ROSE—to assess specimen adequacy at the time of the procedure, while the patient is still available for collection of additional diagnostic material if indicated, and to determine the urgency and [necessity of additional testing](#) as part of the specimen analysis. From the cytopathologist’s perspective, addressing a direct question from an anxious patient for which there might not be a clear answer is, at the very least, awkward.

Cytopathologists have different approaches to these sorts of situations, especially if a preliminary diagnosis represents potential “[bad news](#)” or when cursory examination of the slides is fraught with uncertainty. In some cases, organizations and systems can be designed so that this situation does not arise (i.e., when the pathologist and his or her microscope are physically separate from the patient’s room) [1]. In others, physical proximity will render these sorts of patient-cytopathologist interactions more routine, commonplace, and perhaps even expected. To address the question posed, it is useful to consider the professional responsibility of pathologists as distinct from the complexities of communicating uncertainty to a patient.

Ownership and Responsibility to Disclose to the Patient and the Referring Physician

By nature of training, accreditation, and professional standing, pathologists are physicians and subject to the same standards and expectations as all physicians. In many cases, pathologists are physically detached from the patients whose care they influence, but physical separation does not obviate pathologists’ duty to patients whose cells appear on a slide. In this regard, the obligation and responsibility of a pathologist are very

different from those of a laboratory technician who might face a similar situation, as the pathologist has a sense of professional ownership in cases and has to honor the fidelity intrinsic to all physician-patient relationships.

Obligation to disclose to the patient. Principles of honesty and good faith apply to all physicians, so evading an [obligation to share a preliminary diagnosis](#) with a patient who desires that information can be perceived as dishonest and could have deleterious effects on the patient's emotional state and trust in the health care system. Jay Katz's landmark work, *The Silent World of Doctor and Patient*, clearly makes the case for open and earnest dialogue and vociferously rejects physician silence [2]. Direct communication between the pathologist and his or her clinical colleagues is a central tenet of professionalism, and the same honesty and openness apply to the patient-pathologist relationship. Essentially serving as a physician liaison between his clinical colleagues and his patient (and the specimen itself), Dr. H need not hide behind the microscope; instead, he should feel empowered to share a preliminary impression with the patient *if he chooses*. The nuanced way in which this information is disclosed is, of course, critical.

Obligation to disclose to the patient's referring physician. As is increasingly true in today's practice of medicine, patient care is team-based. In this case, it might be presumed that the oncologist and referring physician who diagnosed Mr. Smith's abdominal mass or treated his melanoma has an established relationship with Mr. Smith and that Dr. H is a "new face." One critical consideration in such cases is to ensure that Mr. Smith's care is not fragmented by the practical reality of subspecialized care or by [transitions in care](#) from one physician to another. The importance of communication between Dr. H and Mr. Smith's other consulting physicians cannot be overstated.

Dr. H must recognize that he is part of a multidisciplinary cadre that consists of Mr. Smith's clinicians, and that sharing a preliminary diagnosis is only the first step toward management of Mr. Smith's lesion. The referring physician presumably knows more about Mr. Smith and is in the best position to use the diagnostic information at hand for advising the patient about next steps.

Often, a patient's questions for the cytopathologist pertain not only to the preliminary diagnosis but also to the implications of that diagnosis for prognosis and subsequent management. These issues, of course, are best addressed by the referring clinician. Therefore, it is necessary for the pathologist to make the referring physician aware of the events and details surrounding the FNA procedure, including the working diagnosis—emphasizing that it is only a preliminary diagnosis—and what the patient knows. This way, the clinician can prepare to engage in a conversation with the patient who is undoubtedly anxiously awaiting more information. Such instances can even stimulate [collaborative dialogue](#) between cytopathologists and referring clinicians about best practices for sharing preliminary diagnostic impressions with patients.

Uncertainty as a Barrier to Disclosure

Like all medical interactions, each patient encounter involving a pathologist is unique, and different factors affect the comfort level and openness of the discourse. There are two major [barriers to disclosure](#) of information in this case, both relating to uncertainty.

Diagnostic uncertainty. In this scenario, the cytopathologist providing ROSE is uncertain about the diagnosis at the time of the procedure, even if he or she suspects malignancy, and is thus unsure of the clinical management implications of the eventual diagnosis. Second, the cytopathologist's ability to [communicate uncertainty](#) to the patient might be limited both by the absence of established patient-physician rapport and by the pathologist's lack of familiarity with the patient's disease trajectory and prior history. In addition, pathologists in general have less direct patient contact than other physicians, which might make them feel less equipped or comfortable engaging in difficult, emotion-laden conversations that require admission of uncertainty or potential error [3, 4]. However, reticence among physicians to disclose errors and admit uncertainty is not a problem unique to pathologists [5].

Assuming that Dr. H is comfortable disclosing information at the time of the encounter, it is important for him to emphasize that the preliminary diagnosis is, in fact, preliminary. He should tell the patient that the preliminary diagnosis is subject to change based upon further microscopic evaluation of the entire specimen and slides and possibly additional tests on the sample (e.g., immunohistochemistry and molecular diagnostic testing). One challenge in communicating this information is to avoid an error often committed by physicians in any specialty when sharing difficult news: using medical jargon and dwelling on details that are confusing and less relevant to the main message. In other words, statements such as "Based on what I see preliminarily under the microscope, I am concerned" or "I am worried about the possibility of cancer here, but I am not entirely sure," will resonate very differently than "the cells are polymorphous and have prominent nucleoli.... S100 immunohistochemistry is necessary for clarification."

This case is particularly tricky because the preliminary diagnosis represents "bad news" and, at the same time, is fraught with uncertainty about the exact nature of the malignant cells (metastatic melanoma versus another neoplastic entity). Patient-physician encounters that involve disclosure of bad news must strike a balance between sharing information openly and recognizing uncertainty, all while demonstrating compassion. Thus, it would also be entirely reasonable for Dr. H to state honestly that he understands and can [empathize](#) with Mr. Smith's concern but is not at liberty to provide exact, specific, and potentially speculative diagnostic information based purely upon the rapid onsite evaluation, the primary purpose of which is to ensure that the sample is adequate for the lab testing that will follow. On the other hand, if the cytopathologist's preliminary impression is that of a benign process, he or she might reassure the patient

accordingly. Nonetheless, the cytopathologist needs to disclose to the patient that only a portion of the material is being examined microscopically at the time of the procedure and that the possibility of discovering abnormal cells upon review of the entire specimen still exists.

Uncertainty about legal liability. Another consideration that can affect the cytopathologist's behavior in this case is fear of legal liability and [malpractice](#). The uncertainty inherent in the interpretation of a subset of FNA cases has been the subject of intense scrutiny and led to a movement in which this uncertainty and the potential for discrepancy between preliminary and final diagnoses is articulated in formal pathology reports [6]. One method of codifying this information is adoption of "common language" for result reporting, which is now standard for reporting Pap testing and thyroid nodule FNA biopsies [7, 8], and which recognizes the uncertainty of cytopathology diagnoses within the result itself (e.g., "follicular lesion of undetermined significance" is one of the six diagnostic categories in the Bethesda System for Reporting Thyroid Cytopathology [9]) [7, 8]. Other fields are adopting similar language that relates not only to diagnosis but also to subsequent steps in management of care [10]. Moving a step further, [quality assurance standards](#) require clear communication of the diagnosis and its implications—and the limitations thereof—as well as technical consistency, as articulated in a classic set of professional guidelines from the Papanicolaou Society of Cytopathology [11].

Conclusion

There is no doubt that Dr. H is, indeed, Mr. Smith's doctor in this setting. Thus, it would be appropriate—and, in fact, very reasonable—for Dr. H to share his initial preliminary diagnostic impression with Mr. Smith. Essential to such a conversation would be the need to articulate uncertainty about both the ultimate diagnosis and next steps. In addition, the involvement and notification of the referring physician would be obligatory, both for care coordination and to ensure that Mr. Smith receives a consistent message. Nevertheless, Dr. H should defer disclosure in this setting for the reasons just discussed. However, this does not liberate him from his inviolable obligation to provide comfort and compassion to Mr. Smith and coordination of his care moving forward.

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ETHICS CASE

Requests for VIP Treatment in Pathology: Implications for Social Justice and Systems-Based Practice

Commentary by Virginia Sheffield and Lauren B. Smith, MD

Abstract

Preferential treatment of patients whom we deem “very important” is a practice that is common in our health care system. The impact of this designation and the care that results is rarely studied or scrutinized. Although we assume that this type of treatment results in superior outcomes, this assumption can be wrong for a variety of reasons, which we discuss here. In addition to expressing unjust preferential treatment for some patients and not others, VIP medicine could compromise patient safety.

Case

Javier, the surgical pathology resident on duty, gets a call about a biopsy performed for a “VIP” patient who is an important hospital donor. A handwritten note from the department chair accompanies the specimen: “Take good care of Mr. Armstrong and make sure his biopsy gets read immediately.” The laboratory technician has already gone home, and Javier wonders why this biopsy should be handled more quickly than others. “All of the patients whose samples are in this lab want their results as soon as possible,” Javier reasons. “They’re all worried about their results. Why should I prioritize Mr. Armstrong’s sample?” He is, however, concerned about the personal and professional consequences of defying orders from the chair of his department. He feels pressured, and he wonders what to do.

Commentary

It is common practice to [treat VIP patients differently](#) from the time they enter the system until the day they are discharged. There are many ways in which status and privilege—most notably, the ability to pay—enter into the health care system and affect patients’ access to care [1]. Preferential treatment of VIPs can either be blatant, as in the case of celebrities or donors, or more insidious, as when members of the health care team are expected to treat other physicians or their family members preferentially [2-4]. When confronted with the care of a VIP patient, we, as clinicians, feel pressure to provide care that is seamless, hassle-free, and error-free. Although this is what we want for all of our patients, we believe that such care is impossible in our current system, and so we try to circumvent the problems that we know exist. In trying to rectify the inefficiencies

and problems that we know about in treating VIPs, however, we might bypass standard protocols and create new problems with “work-arounds,” actually increasing potential for error and harm [5].

Care of the VIP Surgery Patient

VIP surgery patients might be celebrities, donors, or politicians. Alternatively, they might be neither famous nor wealthy; they can be our colleagues or their family members. There are numerous ways in which VIP patients might receive preferential treatment on a surgical service that affects the care provided in pathology. For example, surgery and pathology intersect in the area of frozen section diagnoses. Prioritization of VIP surgery patients, from whom specimens are obtained, can directly or indirectly lead to VIP demands on pathologists.

VIP patients’ surgeries can be scheduled more quickly, displacing other patients in a crowded operating room (OR) schedule—an aspect of VIP care that violates the principle of social justice and our sense of fairness. We accept that patient surgeries may be prioritized based on the acuity of medical condition or, for elective procedures, on a “first come, first served” basis, but VIP patient surgeries might be scheduled sooner simply on the basis of the patient’s status. This accommodation could easily delay surgery for a non-VIP patient who needs it more urgently, which could lead to long-term harm. For example, delaying surgery could increase the likelihood of spread for certain types of cancer. A systematic practice of prioritizing patients based on social status or other nonclinical characteristics effectively increases disparities in the quality of care patients receive and in their clinical outcomes.

Scheduling is not the only way that VIP patients are treated differently on surgical services. VIP patients in teaching hospitals might demand that attending physicians operate without the assistance of residents or fellows. This demand, if met, can disrupt the procedures and [quality assurance practices](#) in place for surgical care, since academic medical centers rely on trainees as surgical assistants, and most surgeries cannot be performed without their assistance in any setting. This deviation from routine practice could compromise safety and quality in ways not anticipated by the patient at the time of a request. Since trainees play a vital role in the delivery of health care in an academic setting, steps and procedures can be missed if they are asked not to participate.

Care of a VIP Pathology Patient

Preferential care of the surgical biopsy patient can similarly lead to requests for special treatment of samples obtained during the procedure. A surgeon might ask for a frozen section, a technique that is used to make a rapid, if preliminary, diagnosis, while the patient is still in the operating room. This technique is appropriate if biopsy results will change the course of the surgery. For instance, a lymph node dissection might be necessary for certain types of cancer, but it is not necessary for others. Instead of using

the biopsy to guide further surgery, the surgeon of a VIP patient might use it solely to inform the family quickly of a diagnosis. This can be harmful; initial frozen section diagnoses may be inaccurate after being fully processed [6]. This discrepancy could lead to emotional distress on the part of the patient or the family.

In addition to misuse of frozen section diagnosis, surgeons might ask that biopsy specimens be rushed just so that a diagnosis is available sooner. Under normal circumstances, a biopsy sample is obtained in the operating room, during the surgical procedure. It is placed in a fixative (formalin in most cases) and sent to be examined, described, cut, and placed in cassettes. These steps comprise what is known as “grossing the specimen.” On day two, after the sample has been processed and encased in paraffin, the histotechnologist cuts the paraffin block and makes glass slides, which are then delivered to pathology trainees (residents and fellows) in academic centers, who study them after having reviewed the patient’s history. On day three, the trainees present the case to the attending pathologist, and a final report is issued to the clinician who ordered the biopsy. In some cases, additional days could be needed for ancillary studies—special stains, immunohistochemical studies, fluorescence in situ hybridization studies, polymerase chain reaction assays—of the tissue. If complex testing is required, the results might not be available for 7 to 10 days or longer.

The desire to spare a VIP patient this typical waiting time for the biopsy results is understandable, but shortening the time could negatively affect processing and review of the samples and the diagnosis. For example, a suboptimal fixation of a specimen for morphologic examination could result in misdiagnosis. The typical workflow could be disrupted such that some technicians are involved in steps (e.g., grossing, preliminary histopathologic review) typically performed by others [7]. Or the time residents and fellows take to preview cases could be shortened, such that the relevant patient history might not be as thoroughly investigated as it would be when the trainees do not feel rushed. Even if an attending pathologist follows all of the steps that trainees usually perform for non-VIP patients, the case review could be missing an extra level of scrutiny by other members of the team. The attending pathologist might assume more primary responsibility for the preliminary diagnosis of a specimen and for ordering immunohistochemical and ancillary studies and might not follow the typical procedures, all of which could lead to actual delays in diagnosis. An attending pathologist might sidestep typical studies or processes in order to more quickly issue a report on a specimen; this could lead to inaccurate diagnosis and its harms. On the other hand, the stress of caring for a VIP and the fear of error could lead to [unnecessary immunohistochemical stains](#) and molecular tests that could result in more incidental findings or possibly even the wrong diagnosis.

Some of these same opportunities for error arise in situations in which a patient insists that an attending physician in internal medicine perform a procedure, such as a bone

marrow biopsy, that she or he might not have performed in many years, or might not have performed using up-to-date techniques. Guzman and colleagues refer to this phenomenon as “chairperson’s syndrome” and urge hospitals to avoid assuming that VIP patients should be treated only by the most visible clinicians or senior attending physicians [8]. Excluding trainees might have negative consequences for VIP patients, especially when trainees are integral to the care of patients in our hospitals and, therefore, use their skills and knowledge of lab procedures more routinely than their faculty [9].

Professional and Institutional Factors Contributing to Preferential Treatment of VIPs

Medical hierarchy. In addition to ethical issues related to the care of VIPs, the case of Javier includes a situation in which the trainee does not feel comfortable doing what is asked of him by an attending physician. The organizational [structure of medicine is rigidly hierarchical](#)—especially in teaching hospitals where a team might consist of members at all levels of training, from medical students to attending physicians. Trainees often do not feel comfortable disagreeing with a plan set by an attending physician for many reasons [10], including lack of confidence, limited experience, and fear of retribution [10–13]. The trainee is in a vulnerable position since he or she relies on the attending physician for grades, promotion, or recommendation letters. Furthermore, attending physicians are not required to consider opinions of trainees, so if someone does have the courage to express an alternative view, his or her opinion might not, in the end, make any difference. For these reasons, trainees often “pick their battles” and acquiesce to requests that they perceive as misguided but not critically threatening to patient care quality, illegal, or unethical [10]. In the worst case, VIP pressures might induce trainees to accept instructions that truly are unethical, which can, in turn, produce moral distress and, possibly, patient harm. If situations that cause moral distress are repeated over the long term, trainees can develop moral desensitization (i.e., acceptance over time of what was once found morally unacceptable) and consequently view requests for special treatment of VIPs as a trivial exception to practice routines when they themselves rise in the hierarchy.

Residents’ acquiescence to attending physicians’ instructions with which they disagree can pose difficult problems, such as fear of retaliation or reprisals. Attending physicians might have not completely considered the ethical implications of VIP care or might have come to accept that it is condoned by the institution and, for the same reasons as those of their trainees, might not have questioned it with their own authority figures.

Hierarchy does not exist only between trainees and attending physicians. Attending physicians have similar concerns when it comes to requests from departmental chairs, hospital administrators, deans of medical schools, or hospital executives. Requests to give special treatment to a patient often come from the development or fundraising office and are sanctioned by hospital leadership, creating a culture in which an attending

physician can feel powerless to say no to VIP requests and accept them as a normal part of practice.

Solicitation of donations. Most hospitals have development offices that seek contributions from [wealthy donors](#) [14-15]. Donors have a variety of personal or professional reasons for wishing to contribute to large academic or other medical centers; in some cases, they might be “grateful patients.” These people might be approached following medical care and asked to fund a particular physician’s research or to give to other areas relevant to their personal medical history. Although these fundraising practices are not inherently unethical, careful planning is required to ensure that privacy and confidentiality are not breached in finding and soliciting these patients [14]. The same concerns with VIP care also exist with this group of patients.

Recommendations

As in the case of Javier, it is difficult to resist prioritizing a VIP’s care on a case-by-case basis. Instead, institutions should actively discourage any systematic prioritization of VIP patients. Development offices should not facilitate scheduling or be allowed to interfere with policies and procedures that apply to patients served by an institution. Hospital administrators and executives might not understand the possible harms that assumptions or unspoken promises of preferential care can cause to a system already rife with disparities. In addition to the obvious concerns about fairness and justice, the increased risk of error, discussed earlier, might not be understood or anticipated by those not involved in the day-to-day care of patients. Patient education might also be needed so that donors and other VIPs do not have unrealistic expectations about access and care. For example, preoperative informed consent discussions could correct the misconception that residents are underqualified [16] or that rushing biopsy results is harmless. The fact that the hospital follows a standard procedure for planning medical care might inconvenience VIPs, but the rationale is compelling and could even be reassuring to a person requesting exceptional service [7, 17]. If the wait for lab results or other inconveniences are truly burdensome, attempts should be made to fix the problem for all patients.

If patients are celebrities or familiar political figures, reasonable attempts should be made to protect their privacy [4-5, 7]. However, expressions or endorsements of favoritism should not be tolerated by organizations or by professionals. It is difficult to resist pressure that members of a medical team might feel when treating a colleague or a colleague’s family member. The adaptations that might be required to favor a VIP patient can be a source of harm, so organizations and professionals should resist the temptation to capitulate to favoritism requests that prompt deviations from typical workflow. Practices and procedures that are efficient and motivate team-based quality performance should be followed to reduce both the potential for stress on the part of the professional and the potential for harm to the patient [2, 5, 9, 17, 18].

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ETHICS CASE

Ordering Stains That Aren't Indicated

Commentary by Martin J. Magers, MD, and Sandro K. Cinti, MD

Abstract

The pathologist rarely interacts with patients face-to-face, but he or she nonetheless maintains a crucial relationship with the patient (i.e., the patient-pathologist relationship). A more tangible relationship, the pathologist-clinician relationship, is typically augmented by the patient-pathologist relationship, but at times the two distinct relationships are at odds, creating ethical dilemmas for the pathologist. This case study and discussion highlight some of these potential ethical questions and underscore the need for pathologists and clinicians to have cooperative, collaborative, and professional relationships. Pathologists should feel empowered to guide the clinician's use of appropriate clinical testing to ensure proper management of the patient and responsible use of health care resources.

Case

Dr. B is in the process of executing a retroperitoneal soft tissue mass biopsy. Midway through, she gets a call from Dr. M, who asks her to apply additional stains to this specimen, which Dr. M believes will identify the possible cause of a patient's infection. Based on her original assessment of the sample, however, Dr. B believes that the so-called "bug stains" will not help diagnose the cause of this patient's illness, that they are not indicated in this case, and that ordering them would require resources that would probably be wasted. If any additional testing is performed, Dr. B thinks that tissue cultures would be more likely to identify the cause of the infection. At the same time, she wants to maintain a good professional relationship with Dr. M, so she wonders if she should just apply the additional stains to avoid disagreement.

Commentary

This case study explores two relationships that are central to the pathologist: the patient-pathologist relationship and the pathologist-clinician relationship. The pathologist-clinician interaction is a routine and visible component of modern medicine, but the patient-pathologist relationship is less obvious [1]. Although pathologists rarely interact with their patients, they are still bound by the Hippocratic Oath to treat and prevent disease [2]. This commitment, however, manifests differently for pathologists than for other clinicians and is worthy of discussion in cases such as this one.

The Patient-Pathologist Relationship

The patient-pathologist relationship is unique in medicine; most patient care responsibilities undertaken by a pathologist never involve face-to-face interaction with a living patient. These responsibilities can include interpreting a biopsy specimen, surgical resection, or cytology fluid sample; reviewing a peripheral blood smear or flow cytometry plots; maintaining a chemistry, microbiology, hematology, or molecular laboratory; or performing an autopsy. Because these responsibilities can involve sensitive information gleaned from patients' specimens, pathologists are obligated to protect patients' privacy, to ensure that a specimen remains uniquely identified with a specific patient, and to treat patients' specimens, parts, and bodies with respect [1].

Another—and perhaps the greatest—obligation pathologists have to patients is to provide pathology results that fellow clinicians can rely on when caring directly for patients [1]; pathology diagnostic information must be regarded by pathologists' clinician colleagues as factual, reliable, and helpful in the diagnostic process. This is typically the case, as the clinically significant diagnostic error rate has been reproducibly found to be less than 1.2 percent, which, while not perfect, does provide enough reliability for clinical management of patients [3-8]. Steps taken by pathologists to mitigate the risk of [misdiagnosis](#) include mandatory continuing medical education, institutional quality assurance programs, and utilization of expert consultative services.

One of the pathologist's many roles is directing laboratories and ensuring that quality testing is available for patients. An ideal test would not only be inexpensive but also have 100 percent sensitivity (i.e., correctly identify all patients who have a disease) and 100 percent specificity (i.e., correctly identify all patients who *don't* have a disease). This ideal, however, is not the reality of laboratory testing because sensitivity and specificity are typically in opposition. Thus, if a test is highly sensitive but not specific and is performed on a patient with a low likelihood of having the disease, there is a high risk of a false positive result. False positive results lead to additional testing, which adds financial cost, and they also can cause anxiety in the patient. Screening men with serum prostate-specific antigen (PSA) testing to detect prostate cancer is one example of such a test; it is no longer recommended by the US Preventive Services Task Force, and men with false positive PSA results are prone to anxiety and sexual dysfunction [9-11]. In such cases, the pathologist must help educate the public and clinician colleagues concerning laboratory testing [1].

A less obvious aspect of a pathologist's obligation to patients is to control costs. [The Patient Protection and Affordable Care Act](#) mandates both quality patient care and overall affordability of health insurance plans [12]. Inefficient or wasteful use of laboratory resources increases the cost of health care [13-15]. Laboratory and pathology testing accounts for at least 4 percent of total health care costs in the US [16], a number that is likely to rise with increased availability of molecular testing. Consequently, test

utilization programs and lab formulary committees have been implemented in both large and small academic health care organizations to monitor costs and implement substantial cost savings when necessary [15, 17, 18]. Thus, pathologists should [communicate effectively](#) with clinicians to try to ensure that only indicated tests are ordered.

The Pathologist-Clinician Relationship

Nature of the relationship. While the patient-pathologist relationship is indirect, the pathologist-clinician relationship is visible and direct. Pathologists provide laboratory data and consultation services that are vital to helping clinician colleagues manage direct patient care. The clinician caring directly for a patient can be viewed as a mediator between a pathologist and a patient and as an interpreter of information generated by pathologists that has implications for a patient. Thus, pathologists have responsibilities to “develop habits and dispositions that further his or her relationships with clinical physicians” [1]. A strong pathologist-clinician relationship based on effective communication and mutual respect ultimately results in better and more cost-effective health care for a patient [19]. Because proper test utilization is imperative, pathologists have obligations to help a clinician colleague order tests that can be aptly applied to helping a patient; they should be familiar not only with the performance of a test but also with a patient’s clinical circumstances and the possible clinical and ethical implications of a test result for that specific patient [20].

Handling disagreement. Disagreements between health care professionals are inevitable. Stempsey acknowledges the potential for tension between the pathologist and other clinicians: “The pathologist’s being outside of the mainstream of clinical practice can sometimes lead the clinician to take the pathologist for granted and can leave the pathologist frustrated and feeling unappreciated” [1]. Awareness of this possibility can be a first step to resolving disagreements that arise, perhaps specifically about the kinds of tests that should be ordered for a patient or more generally about the goals of care for a patient. Pathologists and other clinicians all have obligations to try to identify and address problems in communication; failure to do so could have disastrous results for the patient. For example, suppose a pathologist pages a clinician with a critical result (i.e., that a peripheral blood smear is suspicious for acute promyelocytic leukemia), but the page is never received by the clinician and the pathologist does not follow up on the result because of interpersonal conflict between the two physicians; because of this communication lapse, the patient does not receive life-saving therapy (i.e., all-trans retinoic acid) immediately. Most hospitals and health centers have created codes of conduct that outline procedures for mediating intraprofessional problems, including patient care management disagreements [21].

Application to this Case

This case raises several practical and ethical questions: Should a pathologist suggest more appropriate laboratory testing when a test that’s not indicated or not likely to be

helpful is ordered by a clinician colleague for a patient? Is it ethical for pathologists to perform tests they think are not indicated or not likely to be helpful for the sake of avoiding potential disagreement with a clinician colleague? If so, is it acceptable for the patient to pay the additional cost?

In this case, the pathologist, Dr. B, believes that applying additional stains will not help in the patient's diagnosis and is not indicated. For these reasons, it would be ethical for Dr. B not to perform the requested testing, which would increase financial cost to the hospital and to the patient, possibly lead to additional [unwarranted testing](#) or treatment, and, in the case of a false positive result, could cause unnecessary anxiety or incur other risks for the patient. Health care [resources are limited](#), and it would be unethical to knowingly misuse or waste them. Dr. B certainly could recommend an alternative test, such as tissue cultures, if she feels they are indicated.

Careful morphologic assessment of a histology slide typically mitigates the need for use of additional stains. For example, some infectious organisms (e.g., *Helicobacter pylori*) can be identified with routine histology even though (more expensive) special stains are available for this purpose [22, 23]. Conversely, some infectious organisms (e.g., *Mycobacterium tuberculosis*) do require ancillary testing, such as special staining or culture techniques. In the case of inconspicuous organisms that require further staining, communication between a clinician directly caring for the patient and a pathologist regarding next steps is essential. For example, suppose granulomatous inflammation is present in a lung biopsy and a clinician informs the pathologist that the patient has lived in an area endemic for *M. tuberculosis*; in this set of circumstances, an acid-fast stain (i.e., Ziehl-Neelsen stain) for mycobacteria is certainly warranted. On the other hand, if the alveolated lung parenchyma is unremarkable and without an inflammatory infiltrate, applying an acid-fast stain would most likely represent poor use of resources. If a clinician suspects tuberculous infection, a pathologist could advise her or him to obtain samples for culture or for molecular diagnostic techniques.

It should be noted that, in this case, Dr. B appears to possess a sample that is formalin-fixed and paraffin-embedded (FFPE) tissue. Thus, Dr. B's tissue sample can no longer be used for culture techniques. Newer, molecular-based assays for detection of microbial organisms can be performed on FFPE, but these assays cost more than the "bug stains" (e.g., Gömöri methenamine silver or Brown-Hopps). The high financial cost with better sensitivity and specificity of the molecular assays should be weighed against both the lower financial cost with worse sensitivity and specificity of the routine "bug stains" and the cost and practicality of obtaining fresh tissue for culture by performing another biopsy on a patient. Ideally, the decision of which test to order should be made collaboratively by pathologist and clinician. If they communicate well regarding the differential diagnosis prior to an initial biopsy or resection, then the patient's tissue can be sent for culture at the time of the procedure.

In the case, Dr. B considers simply performing the requested staining to appease Dr. M and maintain a cordial, collegial relationship. Although this is common practice, it puts Dr. B's professional relationship with her colleague before the interest of the patient and could therefore be considered unethical. Medicine is now firmly [evidence based](#), and patient care decisions should be based on evidence, not on clinicians' interpersonal relationship dynamics. A pathologist-clinician relationship, particularly one in which one professional feels unable to express an opinion, is dysfunctional and is more likely to cause harm to a patient than one in which both professionals communicate openly. A good example of possible harm comes from transfusion medicine and inappropriate use of blood products. For example, although serious adverse reactions are rare, blood component transfusion entails risk to the patient of adverse reactions, such as hemolysis, allergic reaction, transfusion-associated circulatory overload, or transfusion-related acute lung injury. Long-term sequelae, such as alloimmunization or iron-overload, are also possible harms [24]. Thus, a pathologist who is unable or afraid to communicate clearly with or to approach a clinician who might be misusing blood bank resources could be putting his or her patients at unnecessary risk for harm.

Furthermore, even if no adverse outcomes occur, patients, professionals, and organizations should not bear the financial responsibility for ensuring a cordial relationship between two clinicians. No patient should have to pay for testing that is not evidence based. Moreover, in the experience of one of the authors (MJM), fee codes for surgical pathology services that are ultimately deemed unnecessary by the attending pathologist during sign-out of surgical pathology cases, such as additional stains, are often removed from the billing portions of reports, thus placing financial burdens of the already-performed tests on the pathology department. In the case of transfusion medicine, blood products are limited resources, and it is not uncommon for blood bank reserves to be low. Giving a blood product to a patient who will not experience a benefit not only increases costs but also potentially leaves a patient who needs the transfusion more urgently at risk of not receiving it.

Conclusion

In summary, it is important for pathologists and clinicians to have cooperative, collaborative, professional relationships that allow for open discussion of ideas and are informed by evidence. Pathologists, as the mediators of laboratory medicine, should not hesitate to question requests for testing that's not clinically indicated and should not hesitate to recommend more suitable approaches that meet a patient's and clinicians' needs. Sometimes, it is in the best interest of a patient for a pathologist to deny certain laboratory testing or services, and a patient should never be held financially responsible for wasted health care resources.

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THE CODE SAYS

The AMA *Code of Medical Ethics*' Opinions Applicable to Pathology

Danielle Hahn Chaet, MSB

The AMA *Code of Medical Ethics* does not have any opinions that address pathologists or the ethics of pathology specifically. The *Code* does, however, offer guidance on [confidentiality postmortem](#) and [consent for autopsy](#), which is helpful for pathologists who are working on cases involving deceased patients.

Confidentiality Postmortem

Opinion 5.051, "Confidentiality of Medical Information Postmortem" [1], generally follows the [standards of confidentiality](#) for patients who are not deceased. As stated in the opinion, "At their strongest, confidentiality protections after death would be equal to those in force during a patient's life." However, certain aspects of postmortem confidentiality should be noted; for example, if a physician is considering disclosing identified information after the death of a patient, he or she should consider imminent harm or potential benefit to identifiable persons or the public health, any statements or directives made by the patient prior to dying, the impact that disclosure could have on the deceased patient's reputation, or "personal gain for the physician that may unduly influence professional obligations of confidentiality." Because pathologists often have access to detailed information about a patient's medical circumstances at the time of death, these guidelines are particularly important.

Consent for Autopsy

Opinion 5.051 also states, "When a family member or other decision maker has given consent to an autopsy, physicians may disclose the results of the autopsy to the individual(s) that granted consent to the procedure." This statement implies that when an autopsy is not required by law (as it might be in criminal cases) but is performed as a result of other circumstances (such as to confirm cause of death), the pathologist may perform his or her duties only after consent has been obtained to do so.

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MEDICAL EDUCATION

Improving Pathologists' Communication Skills

Suzanne Dintzis, MD, PhD

Abstract

The 2015 Institute of Medicine report on diagnostic error has placed a national spotlight on the importance of improving communication among clinicians and between clinicians and patients [1]. The report emphasizes the critical role that communication plays in patient safety and outlines ways that pathologists can support this process. Despite recognition of communication as an essential element in patient care, pathologists currently undergo limited (if any) formal training in communication skills. To address this gap, we at the University of Washington Medical Center developed communication training with the goal of establishing best practice procedures for effective pathology communication. The course includes lectures, role playing, and simulated clinician-pathologist interactions for training and evaluation of pathology communication performance. Providing communication training can help create reliable communication pathways that anticipate and address potential barriers and errors before they happen.

Introduction

In 1977 two 747 aircraft crashed on the runway in Tenerife, the worst disaster in aviation history. Root cause analysis identified miscommunication due to cross-cultural language variations and improper terminology usage among a Dutch KLM crew, an American Pam Am crew, and a Spanish air traffic controller as the primary cause of 583 passenger deaths. The National Aeronautics and Space Administration (NASA) conducted a study of jet transportation accidents between 1968 and 1976 and concluded that pilot error was more likely due to failures in team communication and coordination than technical proficiency [2]. Later studies identified "communication problems" as a causal factor in about 70 percent of airline accident reports received at that time [3]. High reliability industries, like aviation, have implemented standardized communication protocols, safety checklists, and simulation training to ensure robust, open, and effective communication channels. Unfortunately, the health care industry has been relatively slow to acknowledge the key role of communication in keeping patients safe.

Accurate and precise communication is a critical responsibility throughout diagnostic processes. A timely diagnosis is meaningless unless important information reaches both

health care professionals and patients in an interpretable and actionable manner. In an 11-year study of sentinel events (2004–2015), the Joint Commission (JC) highlighted the importance of [effective communication](#) in medicine [4]. Consistent with the NASA results, ineffective communication was determined to be one of the root causes of 66 percent of all reported sentinel events.

The complexities of coordinating multiple specialists' communications can serve as a barrier to clear and timely communication. Whether and when critical information is effectively transferred is influenced not only by the method of communication but also by [hierarchies and power dynamics](#) within and among medical teams. Information must pass both horizontally between services (e.g., anesthesia, surgery, pathology) and vertically according to the flow of authority and status among attending physicians, residents, nurses, and technical staff. Vertical hierarchies are accentuated in teaching institutions and can powerfully influence how critical information is communicated. In the JC study, both communication and human factors (including orientation and training) were leading root causes of errors [4]. Lack of attention to robust communication standards in teaching hospitals, where inexperienced trainees rotate through services, can also create potential for serious medical error.

Designing and Implementing a Communication Curriculum in Pathology

Traditionally, there has been little attention to teamwork and communication skills in pathology and laboratory training. The lack of focus on developing effective communication skills represents a major gap in the education of pathologists, as lack of standardized expectations for conversations and explicit communication training could contribute to errors in information transfers between pathologists and other clinicians. Currently, pathology residents learn how to communicate with other medical professionals informally, typically by observing attending pathologists communicate. This poses two learning challenges. First, attending pathologists vary widely in their communication styles and might not be modeling communication well. Second, learning communication skills through apprenticeship is inefficient compared to learning them through an independent communication course, especially since traditional pathology apprenticeships do not focus formally on communication methods.

With these educational barriers in mind, we developed an [interprofessional communication](#) course in 2012 for pathology residents and fellows taught at least annually at the University of Washington Medical Center. The course is partially based on the TeamSTEPPS® program [5]. TeamSTEPPS is an evidence-based teamwork system developed by the Agency for Healthcare Research and Quality (AHRQ) aimed at optimizing communication and teamwork skills among health care professionals. This pathology communication curriculum includes formally structured learning opportunities, such as lectures, role playing, simulated clinician scenarios; and didactic skill-building sessions that emphasize core communication concepts and principles.

The course focuses on the current standards for the basics of communication, obstacles to communication, and communication of serious pathology errors [6-8].

Communication basics. Before communication training, many trainees failed to use standard verbal elements during communication of significant or unexpected surgical pathology findings (critical values). For example, trainees often failed to identify themselves by name and position or did not request that the receiver repeat the diagnostic information to ensure information was received and understood. To address these communication gaps, our training—both traditional didactics and hands-on learning modules—emphasizes communication elements that should be present in all communications that can influence patients' care. These include self-identification by name, position and department; confirmation of name and role of the clinician or staff to whom information is delivered; the name of the patient; the type of procedure; and involved patient body site. Optimal information transfer must include clear identification of the purpose of the communication and, for diagnoses, concise, unambiguous, and accurate delivery. To confirm that the message was received and understood, a "check back," or request that the receiver repeat the diagnostic information back to the trainee, is required. The check back ensures that the receiver fully understands the content of the communication and accepts responsibility for either acting on or delivering the information to be used in appropriate patient care. Additional requirements for communications include inquiring whether the receiver has additional questions or concerns as well as demonstrated [professional demeanor](#).

Tools, such as a framework for structuring communication, are also introduced to provide standardized approaches and set expectations regarding which information should be communicated, how it should be conveyed, and verifying that it is understood as intended. The elements of a proper information transfer are also introduced and practiced. During a proper critical information transfer, the trainee must ensure that the receiver is aware of and has accepted responsibility for the transferred information. When the trainee is uncertain about the communication, it is the trainee's responsibility to clarify as much as possible and to eliminate sources of ambiguity before a conversation is complete. In addition to including the correct and complete elements of a communication, an information transfer requires acknowledgement by both parties that a transfer of critical information has occurred, especially in the face of communication obstacles.

Obstacles to communication. Concise, clear, and effective communication can be difficult even under optimal conditions. During training in minimizing [obstacles to communication](#), residents practice strategies for communicating clearly, such as avoiding environmental distractions, navigating variations in communication styles, and responding to unexpected questions, conflict, or lack of information. Practicing pathologists are familiar with the most common obstacles encountered during

information transfer. For example, a common question in the frozen section setting is whether a procured tumor is primary (e.g., lung, ovary, GI) or represents a metastasis to the organ. When challenged with verifying information about a procured tumor in simulation training, many trainees gave confusing or inappropriate answers. Providing trainees with exposure to common barriers prior to encountering them during a critical conversation affords them opportunities to practice difficult communications in a less stressful environment.

Communication of serious errors. Perhaps the most challenging communications involve communicating serious pathology errors to patients and the clinicians treating them. This is a skill that we believe must be practiced and refined in advance of actual [disclosures of errors](#). Error disclosure communication training includes introduction to the key elements of error disclosure content that both treating clinicians and patients would like communicated to them after an error occurs [9-11]. Following errors, treating clinicians and patients want an explicit statement that an error occurred; information about why the error happened and how recurrences will be prevented; an [apology](#), including an expression of sympathy for all adverse events; and plans for follow-up. Resident physicians undergo didactic training, simulated phone conversations with clinicians, and in-class role playing emphasizing these key elements during their error disclosure module [12-14].

Evaluating Pathology Residents' Performance in the Communication Curriculum

Both before and after completing the course, residents communicate with trained simulated clinicians by phone using scripted scenarios, which are designed to give residents opportunities to practice communication skills ranging from diagnosis reporting to conflict resolution and error disclosure. Audio recordings of resident interactions with simulated clinicians are provided to the residents to enhance performance feedback and allow self-assessment. [Checklists](#) are often used in simulation-based medical education to enhance training and scoring of communications. In order to develop a checklist for determining the proper performance of the individual steps in critical value communications, we analyzed audio communications in terms of their elements and individual practice components using data from our first class. The checklist was refined in subsequent classes for resident evaluation. The completed checklist of 15-20 elements outlines key communication components for evaluating resident performance (see figure1).

Communication Checklist		Key = NP (Not Performed), P (Performed)	
INTRODUCE		Minimum Requirements	
1. Name	NP	P	Last name
2. Position	NP	P	PGY, R#, Fellow
3. Department	NP	P	"Pathology"
CONFIRM		Minimum Requirements	
4. Name of clinician/staff to whom they are speaking	NP	P	Last name
5. Recipient Position/Role	NP	P	PGY, R#, Fellow, Attending, Nurse, etc.
6. Correct patient and procedure/site	NP	P	Must say both
PURPOSE		Minimum Requirements	
7. Clearly identified purpose of call.	NP	P	Clearly state "I am calling because..."
CONTENT		Minimum Requirements	
8. Appropriate terminology	NP	P	Clear, succinct, accurate. No jargon or abbreviations. Standard terminology.
9. Accurate delivery of diagnostic line	NP	P	Clear, succinct, accurate. No jargon or abbreviations. Standard terminology.
CHECK BACK		Minimum Requirements	
10. Recipient clearly repeats diagnosis back to pathologist.	NP	P	Resident elicits clear and accurate response from recipient repeating diagnostic information. Do you have confirmation that your message was clearly received?
CLINICIAN NEEDS ASSESSMENT		Minimum Requirements	
11. Inquire whether clinician has further questions/concerns.	NP	P	e.g. "Do you have any other questions?" "Is there anything else you need?"
PROFESSIONALISM		Minimum Requirements	
12. Appropriate courtesies	NP	P	Appropriately addressed clinician or staff, said thank you.
13. Professional demeanor	NP	P	e.g. calm, positive, respectful
14. Ethical conduct	NP	P	e.g. honest and transparent conduct. Truthful about limitations.

Figure 1. Checklist for critical value pathology communications developed at the University of Washington.

Pre- and posttests of communication skills and post-course evaluation forms demonstrate both objective and subjective improvements in critical value communication skills among resident physicians. Based on pretest and posttest performance averaged over several classes, overall performance on communication improved approximately 15 percent after training. We found that the combination of lectures and hands-on exercises was most effective at helping residents learn to use standard communication elements during critical value conversations. Residents also reported increased confidence in their ability to communicate in difficult situations after training and increased awareness of flaws in their pretest performance as they completed training.

Conclusion

Our resident communication course has provided us with valuable insight into how a simulation-based communication training course can improve residents' skill in transferring information during critical value conversations. Miscommunications can be

reduced by ensuring that introductions are performed, content is clear and complete, and immediate acknowledgement of information receipt is routinely solicited. Exposure to barriers frequently encountered during information transfer can also help mitigate miscommunication of critical patient information. Most importantly, formal communication training serves to emphasize both the connection between communication and medical error and the frequency of miscommunications. Such training allows participants to practice improvement strategies and a repertoire of skills to assist them in daily critical communications.

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IN THE LITERATURE

Error Disclosure in Pathology and Laboratory Medicine: A Review of the Literature

Ifeoma U. Perkins, MD

Abstract

Since the 1990s, the fields of anatomic and clinical pathology have made strong commitments to improving patient safety, including the creation of formal and informal guidelines for assessing and reporting quality lapses. Unfortunately, some medical errors are inevitable. Patient safety experts advocate full and complete disclosure of all serious medical errors in an effort to preserve the patient-physician relationship and minimize the risk of harm to patients. While evidence suggests that most pathologists disclose serious medical errors, many do not disclose such errors to patients. A literature review of articles published on diagnostic error disclosure in pathology and laboratory medicine suggests that there are in fact persistent barriers to the disclosure of diagnostic errors that are specific to pathology. A number of these barriers are considered here, followed by recommendations for improving patient safety in pathology.

Introduction

Error is defined by the Institute of Medicine as “the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim” [1]. Of particular relevance to pathology are [diagnostic errors](#), which might be revealed by pathologists. Regardless of the nature of the error, however, an important component of a clinician’s response after a medical error is full and timely disclosure of that error [2]. Disclosing medical errors not only maintains respect for patient autonomy and supports truth telling but also is strongly desired by patients, particularly if the medical error results in harm or injury [3]. However, existing guidelines for error disclosure offer minimal guidance about how to disclose an error, such as a misdiagnosis or a missing diagnosis by another clinician. Dintzis et al. found that while 95.2 percent of 169 surveyed anatomic pathologists and laboratory medical directors reported having been involved with an error at some point in their clinical practices, only 88.8 percent reported disclosing an error [4]. And a much smaller proportion—16.2 percent—reported disclosing a serious error directly to the patient whom it affected. In the rest of this review, I examine errors in pathology and laboratory medicine, barriers to error disclosure, and opportunities for continued development of this clinically and ethically relevant set of issues.

Disclosing Errors in Pathology and Laboratory Medicine

Among medical errors, studies historically have demonstrated that diagnostic errors are associated with poor patient outcomes [5-8]. When errors occur in pathology and laboratory medicine, they have the capacity to generate profound diagnostic confusion. These errors can take a variety of forms in different subspecialties of pathology. Errors in laboratory medicine and clinical pathology can occur at any point from specimen retrieval through specimen analysis; they are classified broadly as preanalytic phase, analytic phase, and postanalytic phase errors [9, 10]. Preanalytic phase errors take place before the specimen arrives in the pathology lab and comprise the majority of laboratory errors [10]; analytic phase errors take place during the laboratory processing and analysis of the specimen; and post-analytic phase errors take place during the reporting of the lab results to clinicians and clinicians' interpretation of those results [10]. Errors in anatomical pathology similarly can occur in a variety of settings and might involve reporting an incorrect diagnosis or the absence of a correct diagnosis on a submitted tissue specimen. Diagnostic discrepancies, for example, can occur when the pathologist interprets a "frozen section" within a very narrow timeframe (often less than an hour) for the purpose of determining the best immediate clinical management of a patient or when the pathologist renders a final diagnosis *after* the tissue is permanently fixed in formalin days later. Diagnostic errors in anatomic pathology might be classified as missed (not recognized by a pathologist), near-missed (recognized and communicated to the clinical team), or incorrect (the pathologist identifies the diagnostic entity but misinterprets the diagnosis). In other instances, the pathologist might recognize a diagnostic entity but fail to communicate his or her findings or concerns conclusively [11].

Steps have been taken to improve patient safety and quality in anatomic and clinical pathology. Efforts to minimize the frequency of diagnostic errors and improve patient safety have been implemented by many pathology labs [9, 12-14]. Anatomic pathology has also seen the emergence of interdepartmental consensus conferences in which diagnostically challenging cases are presented and discussed at length prior to the diagnostic results being finalized, clinical- and radiographic-pathologic correlation educational conferences, and multidisciplinary oncologic patient management conferences ("tumor boards") [11]. In clinical labs, implementation of [quality assurance](#) requirements by regulatory and accreditation groups such as Clinical Laboratory Improvement Amendments (CLIA) and the College of American Pathologists (CAP) has led to adoption of measures to improve patient safety, such as increased atomization of specimen processing, standardization of quality control procedures, and proficiency testing [9, 12-14]. These measures hold promise to reduce medical errors in clinical laboratory medicine, which are reported to be as low as 0.045 percent—one of the lowest reported error rates for all specialties in medicine [14]—and in anatomic

pathology, although anatomic pathology labs' published estimated rates of error are much more variable [9, 11].

However, even with implementation of safety and quality measures like those mentioned here, medical errors will still happen. As fiduciaries, pathologists and laboratory professionals are obligated not only to strive to avoid preventable medical errors but also to identify and rapidly report errors. However, there are both individual- and systems-based barriers that pathologists face with respect to disclosing medical errors.

Barriers to Disclosure of Errors in Pathology and Laboratory Medicine

In an article published in the *New England Journal of Medicine* in 2013, Gallagher and colleagues explore some of the challenges clinicians face in disclosing medical errors, including someone else's error, and offer insightful guidelines about how to manage such situations [15]. For example, Gallagher et al. cite as barriers to disclosing someone else's error factors such as embarrassment, lack of confidence in one's own personal disclosure skills, and mixed messages from organizations and malpractice insurers regarding how to handle the incident [15]. The authors also recommend full disclosure of all medical errors that cause harm and identify opportunities for institutions to lead in encouraging clinicians to disclose errors. Gallagher et al.'s recommendation of [full disclosure](#) of errors is laudable. However, its application to the discipline of pathology is complicated by additional existing barriers to error disclosure that are specific to pathology and laboratory medicine.

Barrier 1: Unclear definitions of "error" in pathology. A survey commissioned by the Association of Directors of Anatomic and Surgical Pathology (ADASP) Council of 34 ADASP members revealed sizeable differences in what constitutes a medical error in cancer resection specimen assessment [11]. For example, while 74 percent of respondents regarded as an error a discrepancy in a diagnostic report involving a change in the status of a vascular invasion (e.g., from positive involvement of vascular structures with cancer to negative involvement of vascular structures with cancer), 53 percent did not consider omission of the vascular invasion status in a report to be an error. However, positivity of vascular margin status in many cancers such as breast cancer neoplasms often portends a worse prognosis [16-18], and errors and discrepancies in the status of vascular margins have the potential to result in undertreatment or overtreatment of patients. Therefore, efforts are needed to better clarify the definition of error in contexts specific to anatomic pathology and laboratory medicine. With clearer definitions, anatomic pathology labs, health care delivery organizations, and laboratory administrative groups can better work together to develop an atmosphere of transparency and clearer error disclosure plans.

Barrier 2: Patients might not understand the error. In a recent study, Dintzis et al. [4] reported that 49.7 percent of 169 surveyed anatomic pathologists and laboratory medical directors indicated that “the patient would not understand what he or she was being told” as an important consideration that might deter them from [disclosing a serious error to a patient](#) [19]. This study demonstrates that some anatomic and laboratory diagnostics information can be technical, complex, and conceptually challenging to lay people. Full disclosure of an error in pathology, like any error, requires sharing appropriate context, which can involve details of not only a pathologist’s individual decision-making process but also specimen processing and laboratory management. All of these factors might be overwhelming to someone without medical or pathology training. Additionally, nonclinical factors such as health literacy levels and the situational context of disclosures can influence a clinician’s or lay person’s capacity to understand a pathologist’s error.

Barrier 3: Pathologists worry that another clinician might not be able to adequately explain an error to a patient. With the exception of practitioners of a select few subspecialty pathology services, such as cytopathology and transfusion medicine, most pathologists do not regularly interact directly with patients. Rather, pathologists typically work more closely with clinicians who administer direct patient care. In their role as medical consultant, however, pathologists serve on the clinical team taking care of the patient. Consequently, some critical clinical pathology information is communicated indirectly to patients and their loved ones, mediated by clinicians, who regularly and directly interact with patients. Errors in pathology therefore may be committed not only by the pathologist but also by ancillary staff such as laboratory technicians and managers who work closely with the pathologist and the instruments that process the specimen in the pathology lab. When it comes to disclosure of errors that take place in pathology, this trend of indirect and mediated communication continues; an overwhelming majority of error disclosures in pathology are communicated to the patient by nonpathologists [4].

The disclosure of errors in pathology by nonpathology clinicians introduces many of the same challenges revealed by Gallagher and colleagues [15]. Clinicians disclosing someone else’s error—in this case, the error of the pathology team—may find themselves with limited firsthand knowledge of the error event and may not be aware of certain pathology-specific relevant information worth sharing with the patient during the disclosure process. Dintzis et al. found that 40.2 percent of 169 surveyed pathologists and laboratory medical directors would be deterred from informing a patient of a serious error if the pathologist or director felt that “the physician would not be able to explain the error clearly to the patient” [19]. This is not entirely surprising since studies suggest that physicians as a whole often do not feel competent disclosing medical errors [2, 15].

Pathologists who directly disclose their own medical errors to patients benefit from effective communication and an [opportunity to express remorse](#) [20]. However, formal

ethics and professionalism training that facilitates communication skills development is currently lacking in pathology graduate medical education programs [21]. Without such training and having limited opportunities to form a rapport with the patients they serve regularly, pathologists might be concerned about introducing complexities into the error disclosure process if they disclose directly to the patient. Similarly, pathologists worry about increased risks of postdisclosure litigation [2, 4, 15].

Barrier 4: Someone else's error. To complicate matters further, there are instances in which an error discovered by a practicing pathologist might not be his or her error. Examples include:

1. A pathologist or laboratory director discovers a diagnostic error committed by a technician within his or her medical lab.
2. A pathologist or laboratory director discovers a diagnostic error committed by another pathologist or laboratory worker within the clinician's organization.
3. A pathologist or laboratory director discovers a diagnostic error committed by another pathologist or laboratory director from an outside organization.
4. A pathologist discovers a diagnostic error committed by a clinician in the same organization.

In their roles as medical consultants, pathologists and laboratory directors work with an extensive and heterogeneous clientele base consisting of clinicians and pathologists. In disclosing a referring client's potential medical error, therefore, the pathologist must consider the potential harm to his or her professional relationships. When an error is caused by a technician in the lab, additional layers of complexity in the disclosure process are introduced. These include the responsibilities of the technician, the laboratory manager, the laboratory director, and the health care organization to disclose. However, while error disclosure in such circumstances is encouraged by laboratory accrediting organizations, specific guidelines for laboratory directors detailing particulars on the actual error disclosure in such circumstances are lacking. Standardizing specific guidelines delineating what error events should be disclosed, the timing of error disclosure, and parties to whom the event should be disclosed may prove a helpful resource to pathology laboratory directors.

Conclusion

What is to be done? The CAP's and the ADASP's recently released results of the novel Interpretive Diagnostics Error Reduction Project offer practicing anatomic pathologists the following insightful recommendations to minimize errors [22]: timely mandatory and routine case review tailored to each anatomic pathology lab, followed by investigation of "problematic" cases wrought by significant pathologist disagreements and meaningful steps to investigate and rectify the discordance. While work is underway to prevent medical errors and to design procedures for handling them when they occur, managing communication about errors awaits further exploration in the pathology professionalism literature. The benefits of disclosing medical errors—including effective and open

communication and appropriate management of the patient to minimize any further harm—are well described in the literature [23, 24]. However, barriers to disclosure in pathology persist. Furthermore, to whom the pathologist is obligated to disclose an error directly (e.g., the patient, the clinician who interacts directly with a patient, risk managers, departmental medical director) is still largely uncertain. One survey of practicing pathologists found that 48 percent of anatomic pathologists and laboratory medical directors believe that institutional systems for reporting errors are adequate [4]. More efforts and studies are needed to determine how best to encourage pathologists and laboratory directors to disclose medical errors skillfully. Cohesive efforts in pathology to both reduce medical errors and manage communication about medical errors are important as they serve to further our overall efforts in improving patient safety.

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State of the Art and Science

Pathology Image-Sharing on Social Media: Recommendations for Protecting Privacy While Motivating Education

Genevieve M. Crane, MD, PhD, and Jerad M. Gardner, MD

Abstract

There is a rising interest in the use of social media by pathologists. However, the use of pathology images on social media has been debated, particularly gross examination, autopsy, and dermatologic condition photographs. The immediacy of the interactions, increased interest from patients and patient groups, and fewer barriers to public discussion raise additional considerations to ensure patient privacy is protected. Yet these very features all add to the power of social media for educating other physicians and the nonmedical public about disease and for creating better understanding of the important role of pathologists in patient care. The professional and societal benefits are overwhelmingly positive, and we believe the potential for harm is minimal provided common sense and routine patient privacy principles are utilized. We lay out ethical and practical guidelines for pathologists who use social media professionally.

Introduction

The interest in using [social media platforms](#) such as Twitter, Facebook, and Instagram among pathologists and other members of the medical profession is increasing dramatically, and the full potential of this medium in medicine is still evolving [1-4]. For example, Twitter has been used to disseminate and discuss findings from society meetings, as strikingly demonstrated by the 2016 United States and Canadian Academy for Pathology (USCAP) meeting in Seattle, which generated over 19,000 tweets and over 28 million impressions [5, 6]. Pathology discussions on social media also concern updates on diagnostic criteria, such as the recent changes in thyroid cancer classification [7, 8]; World Health Organization (WHO) monographs [9]; regulatory frustrations; and research findings. There are numerous subspecialty interest groups, including a nephrology journal club with over 3,000 followers on Twitter [10] and a variety of pathology discussion groups on Facebook (e.g., dermatopathology and bone and soft tissue pathology, which had over 21,000 and 18,000 members, respectively, in April 2016 [11]). These uses have been a powerful force for establishing collaborations and spreading educational updates. What generates some ethical controversy, however, is sharing pathology images [12].

Sharing images on social media has become an increasingly popular way for pathologists to interact not only with each other but also with clinicians in many fields, students, patients, and even the general public. For example, comments posted by pathologists on social media related to cancer diagnosis and treatment, emerging viruses such as Zika, and brain pathology with traumatic injury as featured in the film *Concussion* are all easily accessible to the public through Google and other Internet search engines [13, 14]. Social media's ability to reach a wide audience has tremendous power [15], but it has also given rise to fears about [potential privacy violations](#). In our experience, this fear is most pronounced among nonusers of social media who are usually less familiar with how these platforms are used.

In this article, we aim to respond to these fears by discussing potential risks and benefits of social media use vis-a-vis traditional publishing in pathology and by suggesting [guidelines](#) to help protect patient privacy. Importantly, the posting of de-identified pathology images on social media does *not* violate the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [16]. Social media posts are, in fact, not materially different from traditional medical journal case report publications, so the same ethical standards should apply to each.

Social Media Supplants the Case Report?

Pathologists assume a natural role as teachers within medicine. Correlating the clinical situation with pathology findings at the gross, cellular, and molecular levels is key to improving our understanding of disease mechanisms. Pathologists' teaching roles are seen at tumor boards, medicine-autopsy conferences, and directly at the microscope with visiting clinical teams. Although pathologists have traditionally attempted to share key findings with a broader audience through peer-reviewed [case reports](#), fewer journals are finding these of sufficient impact for publication because the time to publication is often long, and the ability to interact with others can be limited. Social media offers instantaneous sharing of information with more possibilities for interaction among audience members. Table 1 compares some of the potential advantages and disadvantages of publishing images in traditional journal-based case reports versus social media platforms.

Table 1. Comparison of potential merits and drawbacks of social media and journal-based pathology case reporting

Factors to consider	Social media presentation	Journal-based case report presentation
Timing	Immediate	Variable, but delayed
Review process	Potential for “crowdsourced” review by ongoing public discussion	Formal expert peer review
Patient details	Typically more limited (particularly on Twitter)	Full history and physical often part of report
Access	Public	Public
Audience	Broad: physicians and health care workers but also more accessible to patients and patient groups	Restricted: physicians and health care workers, often within the specific field
Interaction	Facile, immediate	Variable access to online discussions; could require formal letter to editor or direct contact with author(s)
Use for clinical decisions	Not recommended	Can be cited in diagnostic pathology reports

Social media platforms like Twitter and Facebook circumvent some of the limitations of journal-based case reports, enabling pathologists to share—widely and immediately—not only rare or novel findings but also educational “pearls,” unexplained phenomena, or even just beautiful or playful images.

Although image-sharing on social media has an advantage of immediacy and accessibility, one common criticism is that content on social media is not peer reviewed. It is true that posts are not peer reviewed the way most medical journals’ content is, wherein an editor assigns a manuscript to two or three expert reviewers who then provide anonymous comments about a manuscript and offer recommendations for or against its publication. Yet, in a sense, peer review does actually occur on social media in the form of a “crowdsourced” ongoing public discussion, which can include as many other members of the social network—possibly even qualified professional peers—as

wish to comment on an image or debate a case. Rather than merely passing peer review once, as occurs with many journal-based publications, posts on social media must withstand ongoing, instantaneous, real-time commentary, critique, or review by anyone interested in participating.

Image-Sharing in Journal-Based and Social Media Publishing: Same Privacy Protections

Although the accessibility of social media has raised questions about whether more stringent privacy standards should be implemented and enforced, it is easy to forget that journal-based reports are also publicly available, even if access is fee- or library-based. Both publication venues are governed by HIPAA, and [protected health information](#) (PHI) such as name, date of birth, age older than 89 years, geographic division smaller than a state, and record number should never be included in the text or images [17].

However, some types of information not protected under HIPAA could lead to inadvertent identification of an individual, such as specific details about circumstance or disease type (see table 2). We suggest that sufficient [alteration of patient details](#), although not typically used or required in journal-based case reports, be made when posting images or case descriptions via social media. Examples include rounding a patient's age to the nearest decade, modifying anatomic site, or altering clinical history to retain relevance yet obscure specific details that might facilitate recognition of a patient. None of these alterations are legally required, but, from an ethics perspective, they could help allay anxiety about potential privacy violations while preserving educational value. In addition, the 140-character limit on Twitter further restricts the amount of text material that can be presented compared to a journal-based case report, which often includes lengthy, detailed (even if de-identified) clinical information.

Table 2. Guidelines for protecting patient privacy for pathologists using social media

Types of potentially identifying information	Recommendations
Date	Avoid saying, “today I saw a case of rare entity X” or “yesterday I diagnosed entity Y.” Never use dates. Be intentionally vague (“I recently saw an example of...”).
Unusual or newsworthy circumstances	Avoid information disclosure that could allow direct association with a recent crime or accident, such as “I just received this gun-shot bowel and splenectomy from an unfortunate teen.” Consider delay in posting cases that are highly unusual.
Identifying images	Avoid posting full facial images, unique tattoos, or other identifying features without explicit patient permission (ideally, a signed waiver).
Age	Exclude age for patients older than 89 or aggregate ages into a single category of “age 90 or older.” Precise ages with children are also best avoided. Approximate ages are a good idea for all posts even though not legally required.
Geography	Avoid mention of small geographic subdivisions (anything smaller than a state as a general rule) where the patient might have originated.
Anatomic site/patient history	Modifying clinical history is suggested (but not required by HIPAA). Example: if we (the authors) tweet, “left leg mass from 20-year-old woman,” there is a high likelihood that the actual patient’s true sex, age, or anatomic site differs from the information presented in the tweet.

Case reports and small case series do not meet criteria for research under the Code of Federal Regulations, title 45, part 46, “[Protection of Human Subjects](#),” and thus do not require institutional review board approval [18]. Pathology social media posts are clearly similar and do not by themselves qualify as research. Nonetheless, organizational policies regarding publication of cases vary widely and can be more restrictive than either the law or ethical principles require. Some journals, for example, require patient consent

for publication of case reports and patient images, even if they are de-identified. It should be stressed that this is a policy implemented by individual journals; it is not a requirement of HIPAA. Adoption of this kind of consent policy would not be easy to implement in pathology practice, since direct access to patients is limited. Additionally, it could severely restrict pathology education while providing essentially no benefit for patients' safety. Based on personal experience with publishing and examination of the medical literature, the authors posit that the vast majority of pathology educational images currently available in textbooks, websites, lectures, and case reports, for example, have been published without obtaining consent from patients. This is a widely accepted long-standing practice in pathology, and, provided that privacy is protected, the authors find no major ethical problems with this practice. Indeed, were policies to be implemented to require patient consent retroactively, many pathology education resources would vanish. We argue that the benefits of sharing de-identified pathology images without patient consent greatly outweigh the risks.

It should be noted that organizations and academic institutions might have their own policies or guidelines for posting cases to social media outlets. Unless a user wishes to face disciplinary action from an employer, social media posts should adhere to organizational policies even if they are perceived as Luddite or draconian.

Addressing Privacy Concerns for Specific Types of Images

Skin conditions. Skin diseases can alter appearance or create disfigurement in a visible way that can result in patients' feeling socially isolated or rejected. Sharing images of skin disease can thus be more controversial; enhanced caution and sensitivity should be used. That said, sharing these images via social media can present opportunities to educate the public on the nature of these diseases, help improve understanding, and possibly decrease stigma. [Melanoma](#) and other skin cancers are often easily visible to the naked eye; sharing images of these cancers could raise awareness of the importance of self-examination, potentially resulting in earlier diagnosis and better outcomes for some patients. However, images of skin could lead to easier identification of a patient than could gross images of internal organs or microscopic images. One elegant example of this added level of caution is Josette McMichael, a dermatologist and adjunct professor at Emory University who has a special interest in global dermatology and who posts on Twitter and Instagram [19]. Her posts are educational and help raise public awareness about serious medical and social issues abroad, as they show how advanced dermatologic diseases can affect patients in developing countries with limited access to medical care. She shares clinical and pathology images from a variety of sources around the world, including many from countries where cultural or religious views about modesty can generate increased sensitivity about images of patient skin. McMichael has no legal HIPAA obligation to these patients, yet she still takes great caution in carefully maintaining not only patient privacy (e.g., using cropped images to remove background scenery, intentionally altering patient history and country of origin) but also respect for

these overarching cultural and religious views. Compassion, common sense, and great [respect for human rights](#) are excellent antidotes to concerns over patient privacy.

Facial images. Posting identifiable facial images should not be done without proper consent from patients [20]; most institutions have standard informed consent forms [21], which could be adapted for images shared on social media. Particularly striking from both the standpoint of the disease process and the boundaries of patient privacy is an image from the *New England Journal of Medicine* of a man with diffuse melanosis cutis holding his driver's license up to his face for comparison [22]. Further highlighting how connected social media and print-based journals are in terms of patient privacy, this image was frequently re-posted on Twitter with acknowledgement to the source.

It is important to remember that although one may delete a post or tweet, there is no guarantee that an image has not already been saved or downloaded by other users who could then share it again at any time. Images to be shared on social media may be watermarked with the name or username of the copyright holder to help ensure that the owner of the image is recognized even if the image becomes detached from the original post in this way. However, from a privacy perspective, a useful mantra to live by online is this: once an image has been released, it is public forever.

Conclusion

There is no significant difference in physicians' obligations regarding patient privacy when pathology images are shared on social media or published in medical journal case reports. Along with following institutional guidelines, pathologists who share images on social media outlets should take due care to protect patients' privacy by using suggested guidelines, common sense, and the principle of *primum non nocere* ("first, do no harm"). With responsible use of social media, the minimal risk to patients is adequately mitigated, and thoughtful efforts have potential not only to increase public understanding of pathologists' roles in diagnosis and patient care but also to advance education among pathologists and other clinicians.

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POLICY FORUM

Ethical Considerations about EHR-Mediated Results Disclosure and Pathology Information Presented via Patient Portals

Kristina A. Davis, MD, and Lauren B. Smith, MD

Abstract

Electronic health records (EHR) now include patient portals where patients can obtain clinical reports, including notes, radiology reports, and laboratory/anatomic pathology results. Although portals increase patient access to information, no guidelines have been developed for hospitals about appropriate delays in posting different types of pathology reports to the EHR. Delays exist as a matter of policy to allow physicians time to answer questions and provide emotional support when discussing sensitive results with patients. Some types of results are more sensitive than others, however, including results of cancer, genetic, and HIV testing. Ethical questions about patient access to test results online are discussed.

Introduction

The nationally mandated use of [electronic health records](#) (EHR) has resulted in both new opportunities and challenges regarding patients' access to their clinical information. In this era of online patient portals, not only can patients look up their upcoming appointments or request medication refills, they can also see results of clinical laboratory and anatomic pathology testing. While patients have a right to know the contents of their health record, ethical and clinical concerns arise about the timing of results' availability and potential harms stemming from early access to results without a clinician to help interpret and contextualize those results. Currently, access to results and the timeframe in which they become available vary among institutions [1]. Benefits of access must be weighed against the risks of patients' possible misinterpretation of results and the emotional sequelae and stress that could occur when patients learn of abnormal results without adequate clinical guidance.

Timing of Access to Results

There are no mandates regarding whether hospitals should delay [patients' electronic access](#) to test results for a certain period of time to ensure that clinicians are able to discuss results with patients prior to posting them in a patient's portal. Opinions vary, and little research has been done regarding patient preferences or possible harm to patients in receiving results without a clinician being available for discussion and

consultation. One study reported that a small number of patients (up to 8 percent) found the information in the patient portals anxiety-provoking or confusing [2]. In our experience, the time before the results are released to a patient portal differs depending on whether the patient is an inpatient or an outpatient and on the category of report. For example, inpatient results are posted to the portal 24–28 hours after they are completed. Outpatient results are held for variable periods of time depending on the type of result. Point-of-care testing results (e.g., pregnancy tests, glucose) are released on the same day they are performed. Routine laboratory results are released in 3–4 days. Outpatient diagnostic reports such as anatomic pathology, cytology, flow cytometry, and radiology are held for 14 days. HIV testing results are held for 28–31 days and genetic testing results are held for 90 days to allow time for follow-up appointments. The only tests that are not reported to the patient portal at our institution are human leukocyte antigen (HLA) results, because these contain not only patient but also donor information; the primary clinical purpose of these tests is to assess transplant compatibility. Attempts have been made to formulate automated delays in result availability based on the type of report; however, these are not foolproof. Some items that might seem like routine laboratory results can be similar to anatomic pathology reports and contain sensitive and potentially upsetting information.

The Value of Access to Routine Laboratory Results

Patients can benefit from access to routine laboratory results, such as complete blood counts (CBC), [cholesterol results](#), and standard chemistries (e.g., sodium and potassium). Some of this information could be helpful, especially hemoglobin A1c (used in diagnosing and monitoring control of diabetes) and cholesterol values, if patients wish to have these results available for future reference or in tracking any improvement over time. For example, a patient taking a statin to lower cholesterol could benefit from easy access to prior test results. Liver enzymes would also be relevant when taking a statin since liver and muscle damage can be serious side effects. Of course, physicians should also be monitoring these results closely and discussing them with their patients, but some patients might have more peace of mind knowing of abnormal results more quickly or having easy access to the actual values.

Access to EHR can also improve patients' self-reliance and their relationships with clinicians. Studies have found that portals can lead to shared patient and physician responsibility if patients feel empowered to access their own results [3] and might lead to improved outcomes for [diabetes management](#) and other chronic conditions [4]. Access to records can also increase patient-physician trust [3]. Other authors, however, have questioned the ideal of "patient empowerment;" patients could end up feeling that they are to blame for their own poor outcomes since patient vigilance might not change the ultimate outcome in many cases [5].

An important goal of EHR is to have a record that is easily accessed at any medical center for any patient. Access to laboratory values could allow patients to get second opinions

more easily. Having results available to other physicians might minimize unnecessary test duplication [6]. It has also been postulated that patients' access to the electronic records could decrease errors if patients see incorrect information and alert their physicians, although this benefit has not been borne out in practice in some studies [2].

Ethically and Clinically Relevant Problems that Can Arise in Access to Routine Laboratory Results

Although access to CBC and other routine laboratory results might seem reasonably harmless and even beneficial to some, situations do occur in which these results can be upsetting to patients. One example would be the diagnosis of leukemia, which could be made in conjunction with a routine CBC held for pathologist review. Some patients present with unexplained symptoms and their diagnosis of leukemia is a surprise to both patients and clinicians. In our experience, 14-day delays do not exist for these types of results when they are considered part of the routine CBC order. A pathologist's review of peripheral blood smears automatically happens when specific abnormalities exist on a CBC. Other diseases such as chronic lymphoproliferative disorders, myeloproliferative neoplasms, and myelodysplastic syndromes—which vary in their severity and prognosis—can also be diagnosed or strongly suspected with a CBC and morphologic review. All of these disorders can be confusing, and myeloproliferative and myelodysplastic neoplasms tend to be beyond the scope of expertise of a primary care physician; nonetheless, a patient can receive these results at home with access only to the Internet. Preferably, these results would be provided to patients by their primary care physician with the promise of expedited referral to a hematologist or oncologist. In the era of patient portals and physician time constraints, however, the practice of physicians trying to provide their patients with emotional support by verbally explaining abnormal results in person might be over.

Another serious risk of EHR test result disclosure that's not mediated by a physician is that [patients can misinterpret their results](#). For example, a patient could notice that his or her hemoglobin or hematocrit is low and decide to self-treat with iron supplements. This self-treatment could be harmful in patients with anemia of chronic disease, sideroblastic anemia, or thalassemia, as iron can cause gastric upset and iron overload. Patients might also access the Internet if they're trying to understand an abnormal result and don't have access to a clinician's expertise, and information that patients obtain on the Internet can be inaccurate, lead to inappropriate self-treatment, and generate anxiety.

Access to Anatomic and Cytopathology Pathology Reports

Anatomic pathology and cytopathology reports are generated when patients undergo a tissue biopsy, resection, or fine needle aspiration. These are the types of reports that are used when cancer is diagnosed or staged (i.e., when the extent of a cancer's location in the body is determined). Anatomic pathology reports contain technical clinical terminology and are written for physicians' levels of health literacy. In some cases, the

information can be beyond the scope of understanding for even a primary care physician and might require access to a specific specialty literature or a conversation with a pathologist or oncologist to be adequately integrated and understood. Ideally, a patient would receive such results from a clinician, via phone or in person, when emotional support and additional information can be provided in real time. Receiving diagnoses via an electronic portal could become the new norm if physicians fail to personally connect with patients about results. Electronic disclosures can be ethically and clinically problematic, as patients can have many questions and fears. One of the primary duties of a physician, therefore, is not only to alert patients to abnormal results, but also to educate them on their conditions and apprise them of follow-up that will be needed for treatment.

Access to Genetic Testing and HIV Testing Results

Genetic testing. Genetic test results are considered particularly sensitive, especially from a [privacy](#) standpoint [7]. Genetic testing results can be upsetting or life changing, as in the case of Huntington's disease, breast cancer, or a serious congenital condition. [Results of genetic testing](#) can also carry implications for people besides the patient, such as his or her children. Given these concerns about privacy, genetic testing is an area of medicine in which there has typically been a strong commitment to pre- and posttest counseling, which is often performed by a genetic counselor rather than a physician. Genetic testing is unique in that patients can receive information about conditions that might only develop later in life and conditions that might not develop at all. Interpretation of these results should be personalized, as they often depend on close scrutiny of [family trees](#) (pedigrees) in order to tailor the results to a given patient. Given this complexity, genetic results are particularly difficult for patients to understand without the availability of a genetic counselor, who could provide explanations.

Times have changed from the early days of genetic testing in the mid-1990s, however. Mail-order genetic testing companies often bypass any type of one-on-one genetic counseling. As this industry has only recently been regulated, patients could receive results of tests that are not routinely performed in medical practice. Such information could be upsetting if people consent to testing without being well informed about potential risks of learning new information about their genetic makeup. These risks include emotional distress or concerns about privacy. Although health insurance discrimination based on genetic testing results is now illegal [8], patients who have known genetic conditions still do not have equal access to some services, such as affordable long-term care insurance to cover the costs of managing their illness, which is not included under the Genetic Information Nondiscrimination Act of 2008 [8]. Genetic counseling can help patients understand these risks prior to undergoing testing. Due to the complexity of the information and social and familial implications, additional delay in releasing results to an electronic portal could be justified based on the time it takes for physicians and genetic counselors to coordinate appropriate follow-up appointments. As

there is a shortage of genetic counselors nationwide, some have suggested that genomic medicine tools be developed for the patient portals to allow patients to better understand their results without long waits for appointments with genetic counselors [7].

HIV testing. [HIV tests](#), like genetic tests, have typically been considered sensitive information. This judgment is based not only on the seriousness of an HIV diagnosis but also on historical concerns related to stigma and discrimination. Although the life expectancy for HIV/AIDS patients has improved dramatically over the last few decades, social stigma still exists. Extra time for counseling by a physician might be important for an individual patient's well-being. However, it could also be argued from ethical and clinical perspectives that results of HIV tests should be communicated as soon as they are available, since partners of patients would be at risk and could be told.

Optimizing Patient Portal Experiences

The practice of medicine is changing, and patient access to results can be both beneficial and problematic. In order for patients to maximize the benefits and minimize the harms of changes to clinical record maintenance and access, additional research is needed to elicit patients' preferences about electronic access to their test results. Patients might very well differ in their preferences about results reporting. In one study, 40.5 percent of patients wanted results to be communicated differently for malignant and benign diagnoses [9]. While the majority of patients in the same study (51.7 percent) valued rapid results [9], some want information as soon as it's available and others prefer to hear about new information from their physicians. Patient preferences can also change over time based on the stage of disease [10]. It would be desirable if patients could choose which option they prefer in the future. It would be ideal if patient preferences could be built into an electronic health record system. Moreover, patients have been found to have concerns about how their privacy is protected, which will also need to be addressed for increasing patient satisfaction [2, 11, 12]. Of course, a subset of patients—perhaps elders or members of disadvantaged populations—might not be computer literate or have access to a computer [13, 14]; in these cases, other solutions will be necessary [15].

It is important to remember that electronic portal access to laboratory and biopsy results does not abrogate a physician's responsibility to adequately support and educate patients about critical clinical information. Strategic delays in posting to patient portals will be needed to ensure that physicians have sufficient time to contact patients with important medical results. Integrating patient preferences for communicating results into the portals would be ideal. Also, finding alternative ways to emotionally support, educate, and counsel patients could be helpful if physicians will not always be conveying the results of laboratory testing in the Internet era.

Conclusion

The era of electronic health records and patients' access to online, portal-mediated results is not a future challenge; it's a current one. Access to electronically based health data provides patients with opportunities to be more actively engaged in their care. On the other hand, deciding the nature and timing of this access must take into consideration potential harms to patients that can arise from unexpected or potentially confusing results. Finally, in debating what is best for patients, it is incumbent on pathologists and all physicians to remember that patients are individuals with unique preferences that should be addressed as carefully and compassionately as possible.

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MEDICINE AND SOCIETY

The Penetrating Gaze and the Decline of the Autopsy

William E. Stempsey, MD, PhD

Abstract

Understanding the decline in the autopsy rate can be furthered through analysis of Foucault's idea of the medical gaze and the ancient Greek idea of *theoria*. The medical gaze has shifted over time from the surface of the body to the inner organs to the cellular and subcellular levels. Physicians and loved ones of the deceased person are not likely to "gaze" at the same levels. Patients' loved ones might not theorize as physicians do; they have different interests, which suggest the need for more attention to informed consent for autopsies. Responding to this need should take priority over efforts to increase the autopsy rate, and it can also be seen as an opportunity to improve autopsy and autopsy consent practices.

Introduction

The decline of the autopsy rate since 1972 is well documented [1]. Reasons offered include the 1971 decision of the Joint Commission on Accreditation of Hospitals (now the Joint Commission) to eliminate autopsy requirements for hospital accreditation, the high cost of autopsies, the cumbersome process required to [obtain consent](#), and the belief that autopsies have lost their value because of advances in diagnostic testing [2].

Studies of autopsy results provide data that support the continuing importance of the autopsy, despite its decline. One study of autopsy results from 1960, 1970, and 1980 found that in all three decades, roughly 10 percent of autopsies revealed a previously undetected major diagnosis that, if known, might have led to a change in therapy that could have prolonged survival [3]. Another study comparing results of autopsies from a university hospital and a community hospital during 1984-1985 showed similar results and also discovered other "unexpected findings" that, had they been diagnosed premortem, probably would not have improved survival [4]. These findings suggest that the early '80s marked an important shift: improved diagnostics rendered autopsies less necessary and less likely to reveal critical findings, which, if diagnosed earlier, could have made a difference for morbidity or mortality. A 2003 meta-analysis of 45 studies conducted over a period of 40 years showed statistically significant decreases over time in major [diagnostic errors](#), although a major diagnosis remained clinically undetected in at least 8.4 percent of cases. The authors concluded that ongoing use of autopsy is warranted [5], but the evidence of a decrease in major diagnostic errors or an increase in

the acuity of diagnostic technology suggests a less urgent need for autopsy than in the past.

Except in forensic cases, pathologists need permission from loved ones of the deceased person to do autopsies. But informed consent processes of discussing risks and benefits can be difficult for a deceased patient's loved ones, who tend to "see" autopsies in a different light than pathologists. Reluctance to grant permission might be another reason for the decline in the autopsy rate. What can an understanding of habits of perception tell us about all this?

The Clinical Gaze

To understand just how differently pathologists and loved ones of the deceased person tend to view an autopsy, we first examine three aspects of the pathologist's trained perception.

The "anatomy-clinical gaze." Michel Foucault argued that in the late eighteenth century, with the "birth of the clinic," the perceptual "gaze" of physicians shifted from the body's surface to the inner organs, the space of pathological anatomy. Diseases, previously understood by classification of clinically observable symptoms and signs, were now seen as lesions in the depths of tissues. Understanding disease requires that we "open up a few corpses" [6]. Today, technology enables the gaze to focus on smaller histological, cytological, and molecular elements of organs. Through various forms of imaging and tests for pathology at the molecular level, bodies no longer need to be opened up to enable a gaze below the surface. Has technology rendered the methods of Virchow and Rokitansky, the pioneers of pathological anatomy, obsolete?

The technological gaze. Some have gone so far as to suggest that technology has fundamentally altered our perception of disease; Hofmann speaks of the "technological gaze," perception mediated by technological means, in "The Technological Invention of Disease" [7]. That is, technology mediates between the perceiver and the perceived, allowing clinicians to observe representations of morbid anatomy during life. Pompilio and Viera argue that this new paradigm obviates the need for autopsies to correlate symptoms with [pathological anatomy](#); instead, one need only check lab results and images, since these are what define disease [8]. Furthermore, this thinking is already reflected in the idea that "living anatomy" and [medical imaging](#) can replace the use of cadavers in anatomy teaching [9, 10]. It could be that a technological gaze is beginning to replace what Foucault called the "anatomy-clinical gaze," which relied on opening a few corpses.

The theorizing gaze. The ancient Greeks' *theoria* is the root of our word "theory." *Theoria* was originally related to being a spectator. It meant the activity of looking at or considering, and it also referred to the spectacle that is viewed [11]. The common Latin

translation, *contemplatio*, gives us the English “contemplation,” which carries quite lofty connotations for us and might lead us to miss the nuances buried in the Greek *theoria*. “Gazing upon” perhaps more aptly conveys the idea that *theoria* involves some depth. If we bring this notion of *theoria* as gaze to Foucault’s notion of the medical gaze, we see that the theorizing gaze not only looks more deeply into the body, but also contemplates more deeply what the body reveals.

In Book 10 of his *Nicomachean Ethics*, Aristotle calls a life of *theoria* the best, most fulfilling kind of human life [12], although he never fully explains exactly what he means by *theoria*. Philosopher David Roochnik argues that while some interpreters attribute to Aristotle an “exalted” conception of *theoria*—something akin to contemplating necessary truth—a more complex “mundane” conception seems correct when *theoria* is understood in the context of the whole of Aristotle’s writings [13]. Aristotle distinguishes between *theoria* (theorizing), *praxis* (rationally choosing a practical course of action), and *poiesis* (producing something). *Praxis* and *poiesis* are practical and involve objects that are shaped by human beings, but the object of *theoria* is truth itself. While the exalted conception of *theoria* draws a clear line between theorizing and the other two practical conceptions, Roochnik views Aristotle as linking these, as all purposeful human actions and productions involve an element of theorizing [13]. Purposeful and productive action is not merely instinctual, but involves depth of thought that seeks truth. This is a particularly apt understanding of the work of a pathologist, who delves into a patient’s body seeking not only knowledge of the disease of that particular person for practical, patient-centered reasons, but also knowledge of the truth about disease in general.

Although clinicians can have practical concerns such as explaining a death to a deceased person’s loved ones and improving care, they also have a theorizing gaze, as they are concerned with treating more than just this one patient and, like pathologists, want a better understanding of disease processes. When physicians request permission for an autopsy, they are seeking knowledge about various aspects of disease. The deceased patient’s loved ones, however, might have different practical, emotional, ethical, or spiritual concerns, such as expediting the return of the body to prepare for a wake. Their gaze can be affected by overwhelming emotions of grief and even fear, and the information to be gleaned from autopsy might hold relatively little importance for them.

A Patient’s Loved One’s Gaze

The objectifying technological gaze has undoubtedly rendered some families of deceased patients ambivalent about the need to “open up” and look deeply into a particular corpse. But their primary gaze likely remains at the surface, with fresh, raw images of the suffering of a loved one. Some may be altruistic about offering the body for educational purposes, but emotional resistance leads many to not even want to think about such a thing.

Those who have a technological gaze might see dead bodies, now lacking the essence of the person, as nothing more than nonfunctioning biological material. The medical gaze thus can focus on mechanical failure of organs, even if physicians recognize further practical purposes of autopsy such as diagnostic quality control and increasing knowledge that might benefit others. It is far more likely, however, that bereaved family members see the deceased patient's body as a morally significant representation of the person. Memories of a person are based on memories associated with the body. Hence, loved ones of the deceased person can perceive the body as "at once dead and alive" [14] and focus on finding deeper [meaning in that person's death](#). The thought of cutting into the body and removing organs might be abhorrent to them—something that can easily escape the gaze of the pathologist going about everyday work. This dissonance alone cannot explain the decrease in autopsy rates; these feelings of abhorrence and resistance to thinking about death are nothing new. Such considerations, however, do suggest the importance of consent for, and robust discussion of the risks and benefits of, an autopsy.

Improving Informed Consent as a Means of Improving and Increasing Autopsies

What is needed is to de-emphasize getting *permission* for autopsies in order to enable the theorizing gaze, which can lead to knowing more about disease, and instead to emphasize getting *informed* consent. This recommendation might seem counterintuitive, but a frank discussion of the different gazes that are operative could lead to more carefully considered autopsies. Autopsy consent forms often lack information that would be helpful for both physicians and families in making educated decisions about autopsies. A national survey of autopsy consent practices found that over half of chief residents reported deficiencies in their knowledge of autopsy procedures [15]. If chief residents do not fully comprehend all the elements of an autopsy, they cannot explain them; it is hard to see how families could then give informed consent. What is needed is transparency in a conversation between physician and family and a robust discussion of risks and benefits [16]. Matters such as how the procedure is carried out, the retention of organs for teaching purposes, and the possibility of limited autopsies or postmortem use of imaging technology are examples of topics that should be discussed if consent is to be considered informed. Explicit discussion of all these matters manifests the respect due the body during autopsy.

Conclusion

Clinicians, pathologists, and families of a deceased person might gaze on the autopsy differently: families of the deceased might still see a person with whom they have had a significant relationship while clinicians and pathologists might have a more penetrating, objectifying, and theorizing gaze. Appreciating this difference in perception of value might help us to fulfill the ethical requirements of informed consent processes and the important roles autopsies can play in motivating our shared understandings of a person's death. To be clear, the focus should not be primarily on increasing the number

of autopsies performed, but rather on [fostering cooperation](#) between inquiring physicians and grieving families in order to uphold the value of seeking knowledge and to express respect for the deceased person's body. In performing the autopsy, the pathologist, too, needs to direct a penetrating gaze in both of these directions.

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MEDICINE AND SOCIETY

Public Figures, Professional Ethics, and the Media

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Abstract

Death certificates and autopsy reports contain personal identifying information and clinical information protected under the Health Insurance Portability and Accountability Act (HIPAA) of 1996. These documents are used, for example, by the families of the deceased for settling estates, bereavement and closure, and genetic counseling of relatives. Insurance companies, public health and law enforcement officials, and the legal community also have legitimate claims to this information. Critical ethical questions have not yet been settled about whether and when this information should be public and under which circumstances making this kind of information public incurs benefits, harms, or both. Additional considerations include which organizations—the media, academic institutions, or government agencies, for example—are best suited to interpret these questions and respond to them.

The Death of Prince

When superstar musician Prince died earlier this year, fans and media alike clamored for the results of his autopsy. Speculation swirled around the circumstances of his death and whether the medical examiner (ME) would release additional, detailed information. Like many states, Minnesota, where Prince both lived and died, restricts access to autopsy reports. So MEs are only allowed to release cause and manner of death and minimal identifying information [1]. After weeks of waiting for toxicology tests, Prince's cause of death was leaked to the media by a law enforcement official, prompting the ME to release a one-page form identifying the official cause of death as an accidental overdose of fentanyl [2].

Media Interest in Autopsies and the Roles of Pathologists

When other stars, such as Michael Jackson and Whitney Houston, have died, the published autopsy results were quite detailed and painted a picture that allowed independent conclusions about their causes of death to be developed by both the media and fans [3, 4].

The issues of privacy, the role of government, transparency, and the so-called “public’s right to know” (asserted by the media for decades) have complicated the [release of](#)

[autopsy reports](#) to the public. States have taken differing stances on whether and when to release autopsy reports, which gives rise to conflicting priorities among family members, public health and public safety officials, insurance companies, and other stakeholders. These issues have been the subject of ethical, legal, and clinical debate for many decades. As self-appointed “watchdogs” of the public interest, the media considers autopsy reports to be important sources of information. Yet federal law under the [Health Insurance Portability and Accountability Act](#) (HIPAA) of 1996 [5], with some exceptions, protects all individually identifiable health information—referred to as [protected health information](#) (PHI)—including information that “relates to the past, present, or future physical or mental health or condition of any individual [and] the provision of health care to any individual” that “is created or received by a health care provider, health plan, employer, or health care clearinghouse” [6].

Legally, ethically, and clinically relevant, however, is that MEs and coroners are not “covered entities” under HIPAA. To be clear, all MEs are forensic pathologists in appointed positions, while coroners are elected officials. State-to-state variations abound: sixteen states do not have laws requiring coroners to have specific training requirements, and four states require them to be physicians though not necessarily pathologists [7].

HIPAA, Professional Ethics, PHI, and the Public Domain

MEs and coroners are exempt from HIPAA when gathering information while executing their statutory responsibility to determine a cause of death, but a number of ethical questions remain about the extent of HIPAA’s authority to MEs’ and coroners’ practices. Should exemption from HIPAA extend to MEs and coroners when releasing information to the public? Was this exemption intended by the legislature to apply to MEs and coroners for the purpose of investigation only? Does this exemption mean that what would, in other circumstances, be considered PHI and thus not be releasable to the public, is somehow justifiably releasable to the public? If so, why?

In some states, an autopsy report is public record and a death certificate is restricted (e.g., Maryland [8]). In other states, the reverse is true (e.g., Virginia [9]): an autopsy report is restricted and a death certificate is not. So, effectively, in cases in which the deceased person is a public figure, a public record autopsy report (or death certificate, depending on the state) can become a “back door” to revealing restricted information, including PHI, in a death certificate (or autopsy report, depending on the state).

Conflict between promoting the ethical value of transparency by accelerating access to a public figure’s PHI and the right of that public figure to privacy, especially of PHI, is a significant dilemma that Prince’s case illustrates. Some persuaded by the so-called “public’s right to know” might argue that access to deceased patients’ (including public figures’) PHI should be exempt from HIPAA. Others might argue more generally that, since an autopsy is conducted after death, it should not be considered part of any

patient's clinical record. Others might argue, however, that an autopsy report contains clinical information that is PHI, regardless of the person's renown or infamy, and thus should be—from legal, ethical, and clinical perspectives—regarded as private and protected as such by professionals.

The National Association of Medical Examiners, for example, states that “the performance of forensic autopsy is the practice of medicine” [10]. This suggests that an autopsy report is probably regarded by most MEs as an important part of a person's health record and perhaps as PHI. Like other health care professionals, pathologists are legally and ethically obliged to keep PHI confidential. Why should this professional obligation change when a pathologist is determining the cause of a person's—any person's—death?

More Unresolved Ethical Questions

It's no wonder, then, that the demand for Prince's full autopsy report has sparked numerous ethical questions about how state-by-state regulations and laws concerning autopsies should be interpreted. For example, in some states (e.g., Kentucky [11]), if a death is determined to be a coroner's case, an ME or coroner has the authority to order an autopsy without obtaining consent from the deceased person's survivors and to release information about the cause and manner of that person's death to the public. Is this ethically appropriate, particularly considering the legal, ethical, and professional standards that typically apply to patients' rights to have their PHI protected? Which protections should be afforded to the deceased and to a deceased person's loved ones? How much value should be attributed to survivors' distress? When, if ever, should a [person's status as a public figure](#) matter for how we treat their PHI? What constitutes just access for the media, for example, to any person's PHI? What constitutes appropriate scope of a so-called “right” to know, on the part of the public?

These questions will continue to be debated in the media and, most likely, in legislative bodies, for years to come.

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IMAGES OF HEALING AND LEARNING

The Use of Visual Arts as a Window to Diagnosing Medical Pathologies

Katrina A. Bramstedt, PhD, MA

Abstract

Observation is a key step preceding diagnosis, prognostication, and treatment. Careful patient observation is a skill that is learned but rarely explicitly taught. Furthermore, proper clinical observation requires more than a glance; it requires attention to detail. In medical school, the art of learning to look can be taught using the medical humanities and especially visual arts such as paintings and film. Research shows that such training improves not only observation skills but also teamwork, listening skills, and reflective and analytical thinking. Overall, the use of visual arts in medical school curricula can build visual literacy: the capacity to identify and analyze facial features, emotions, and general bodily presentations, including contextual features such as clothing, hair, and body art. With the ability to formulate and convey a detailed “picture” of the patient, clinicians can integrate aesthetic and clinical knowledge, helping facilitate the diagnosing of medical pathologies.

The more one looks, the more one sees.

Dr. Abigail Housen, art educator [1]

Introduction

[Observation skills](#) are required for the practice of medicine, yet they are rarely formally taught in medical school curricula [2]. Observation means careful looking and it is sometimes assumed to have happened when, perhaps, it has not [3]. Derived from the Latin word *observare* (“watch over, note, heed, look to, attend to, guard, regard, comply with” [4]), clinical observation requires more than a casual glance; it requires deft integration of visual information. “Visual literacy” [5] is a kind of aesthetic reasoning informed by careful observation that can help generate meaning, based on the images viewed. Notably, there is no accepted system to teach visual literacy to physicians-in-training. However, [use of visual art forms](#), such as paintings and film, has been integrated into curricula at several medical schools [6-7] (also KAB, unpublished data).

The Value of Visual Literacy in Medicine

Humans are not machines, yet it is easy for medical students, especially those in their preclinical years, to view the body as simply a collection of parts. As students begin to

work with simulated patients (actors) and real patients, they discover other elements that are critical to [whole-person care](#)—namely, emotional, psychological, and spiritual aspects. Although physical presentation is an obvious component of observation, emotions can also be interpreted from facial expressions and body language, and these, together with contextual features such as clothing, hair (dirty, clean, uncombed, finely coiffed) and body art, create a “picture” [8] of the patient and his or her humanness [3].

Visual literacy can inform clinicians about things the patient is not directly telling them that might be relevant to a diagnosis or to good communication. For example, patients who are unable to communicate their symptoms due to their clinical state (e.g., coma, intoxication, or hepatic encephalopathy) may display swollen features or erythema. Some patients withhold information from their clinicians due to embarrassment, fear, and the desire to avoid confrontation [9–10], which might be evident from the presence of perspiration, pallor, or body language. By exploring a patient’s facial expressions [11–12], emotions, body language, and contextual features, clinicians can glean nonverbal cues to support how they care for a patient.

The ability to clearly capture and document what is observed is also an aid to teamwork and collegiality. Clinical team members (including nurses and allied health staff) should be able to read a chart note and envision a [“picture” of the patient](#), as medicine is a multidisciplinary effort. Additionally, a thorough picture of the patient can aid clinical investigators who subsequently review charts during the course of research. As early as the 1800s, the value of such documentation was noted by physician Louis Martinet when he stated, “The report of a case should be like the copy of a picture.... the observer should still express its real character” [8].

The Medical Humanities Curriculum at Bond University Medical School

In 2014, the medical humanities program at Bond University School of Medicine in Queensland, Australia, was formally overhauled. The history of medicine lecture and compulsory reflective film-making assignment (viewed as too technically demanding by some students) were replaced with the following four elements: (1) a 50-minute, noncompulsory Medical Humanities Workshop; (2) a compulsory mixed media art creation and reflective essay assignment; (3) Medical Humanities Week; and (4) the Art is Good Medicine community art exhibit. This medical humanities curriculum is offered during year two of the five-year undergraduate medical degree program.

The Medical Humanities Workshop. This workshop uses visual thinking strategies (see table 1) to teach visual literacy [6]. A clinical ethicist (KAB) leads the session, which introduces students to the concept of medical humanities and reviews evidenced-based support for the value of the medical humanities in medical education [2–3, 5, 13–16].

Table 1. Visual thinking strategies used in the Bond University Medical Humanities Workshop

Students are encouraged to actively listen to and engage with their peers and the creative work (film, poem, painting).
All students are given the opportunity to express their opinion about the creative work.
With the film clip/poem/painting shown on a large screen, the teacher points to and focuses students' attention on features of the creative item displayed.
All student comments are acknowledged by the teacher.
The teacher offers no positive or negative evaluation of student opinions.
The teacher positively affirms students' opinions (i.e., there are no wrong answers or views).

The remainder of the session comprises observational activity, with the class divided into three groups. All three groups perform their observations simultaneously (but separately). With all groups present together the teacher then interacts with each group using visual thinking strategies to draw attention to visual cues and their significance. During this experience, all groups listen to and interact with each other about their observations and interpretations. While wearing headphones/earbuds, Group #1 watches a brief film clip on a laptop or tablet device (e.g., the scene from *The Diving Bell and the Butterfly* [17] in which a doctor describes his ski trip to his patient with locked-in syndrome or the scene from *Silver Linings Playbook* [18] in which a psychiatrist plays anger-triggering music in his clinic waiting room). Group #2 studies an award-winning poem [19] written by a medical student during her oncology rotation. Group #3 studies high-resolution color printouts of a painting (see table 2).

Table 2. Bond University Medical Humanities Workshop teaching images (Group #3)

Painting	Artist	Date	Image
<i>The Madness of Joanna of Castile</i>	Lorenzo Vallés	1866	Joanna refuses burial of her deceased husband (Philip I), believing he will be reanimated [20].
<i>Self-portrait with Dr. Arrieta</i>	Francisco de Goya	1820	The artist is the patient, receiving treatment from his physician [21].
<i>Healing the Deacon Justinian</i>	Giovanni da Fiesole	1443	Saint Cosmas and Saint Damian transplant the (black) leg of a Moor onto the (white) body of deacon Justinian [22].

Note: Images rotate in the curriculum each year.

The mixed media assignment. The compulsory art assignment gives students seven weeks to create a work of mixed media on any topic related to health care (for examples, see figures 1 and 2). Mixed media is the required type of art as this allows students a wide range of creative expression, rather than limiting them to simply drawing or painting. The students also write a 500–1,000 word reflective essay that describes the media, interprets the artwork, and discusses their reasons for creating the artwork. The students submit their essay and a photograph of the artwork for assessment, and the assignment is marked on a 100-point scale using seven marking criteria: (1) the ability of the artwork to communicate the student’s message; (2) photographic quality; (3) quality of descriptive writing; (4) quality of interpretive writing; (5) quality of reflective writing; (6) adequacy of referencing; and (7) grammar, syntax, and spelling. On the rare occasion that a student fails the assignment, it is generally due to not following directions (e.g., creating art that is not mixed media—for example, a pencil sketch or performance art). Artistic talent is not a marking criterion.



Figure 1. *Trauma*, by Sachi Chadha. Reprinted from *Art Is Good Medicine* [23] with permission of the author.



Figure 2. *Too Many Words*, by Hana Yusuf. Reprinted from *Art Is Good Medicine* [24] with permission of the author.

Medical Humanities Week and the Art is Good Medicine community art exhibit. During a five-day period each March, the foyer of the medical school is converted into an art gallery displaying mixed media art creations from the compulsory assignment. Each year, approximately 20-25 students (from a class of approximately 100) volunteer to display their art during Medical Humanities Week. Students and teachers from across the university visit the foyer to view the art. Medical Humanities Week culminates with an evening gala for the local community, giving medical students the opportunity to interact with teachers and fellow students as well as parents and guests attending the free event. The gala also includes a live performance from the Bond University Orchestra. The art is judged by two professionals from the community and an AUD \$100 prize awarded. Teachers also judge the art during the week using an online survey; the winner of the Teachers Choice Award receives an AUD \$50 shopping mall gift card. At the conclusion of the event, an exhibit book is produced and distributed free worldwide on the Internet [23-25].

Compared to the prior curriculum, this revamped curriculum allows students to explore their “creative side” without the pressure of a requirement for technical or artistic skill. The art gallery component promotes direct interactions with peers, teachers, and the community (their future patients). And the use of visual thinking strategies during the workshop gives students an opportunity to deepen their observation skills.

Evaluation of Bond University’s Medical Humanities Curriculum

In April 2016, the impact of Bond’s new medical humanities curriculum was studied using a Human Research Ethics Committee-approved protocol [6].

Method. Feedback was solicited with a voluntary, anonymous, online 15-question survey [26]; no demographic data was collected. Most questions were multiple-choice with an open-ended free text option. (Questions other than Yes/No/Undecided allowed for multiple answers to be selected.) The survey was posted on students' electronic blackboard and the cohort Facebook page, with one survey reminder posted after two weeks.

Participants. The survey was offered to 280 medical students who had taken the curriculum; 23.6 percent ($N = 66$) completed the survey. Three cohorts participated in the evaluation study: Cohort #1, from 2014 ($n = 16$); Cohort #2, from 2015 ($n = 18$); and Cohort #3, from 2016 ($n = 32$). (Since the data were collected from the three cohorts simultaneously, the cohorts had two years, one year, and one month of reflective time after participating in arts education, respectively.) Since taking the curriculum, all student groups would have interacted with both real patients and simulated patients.

Results. The majority of the students supported the addition of arts education to the medical school curriculum (54.6 percent) and keeping arts education in the curriculum (63.6 percent). Upon hearing about the requirement of undertaking the art assignment, many students reported liking the idea (42.4 percent) or being excited about it (39.4 percent). After completing the art assignment, many students felt pride (65.2 percent), a sense of achievement (53.0 percent), and enjoyment (48.5 percent). Most students were comfortable with the quantity of arts education (62.1 percent), although some wanted more of it (18.2 percent) and some less of it (19.7 percent).

All three student groups ranked improvement of reflective thinking as the skill most influenced by arts education. Improvement in observation skills was also ranked among the top three skills by all three cohorts. Interestingly, a large proportion of students from Cohort #1 (2014) and Cohort #3 (2016) indicated that arts education had no impact on their skills (43.8 percent and 40.6 percent, respectively). Perhaps the reflective period for Cohort #1 was too short and Cohort #3 had additional education experiences during their lengthy reflective period that overshadowed anything potentially gained from the arts curriculum.

Furthermore, after engaging with the arts curriculum, 40 percent of students were actively creating art or observing art as a method of stress relief. This finding is important due to the high-stress nature of medical education and the attendant psychosocial and health risks that students face [27, 28]. Additional data from the evaluation study are presented in table 3.

Table 3. Partial data from the Bond University medical humanities curriculum evaluation study

Question	<u>No. (%) of students</u>			
	Cohort #1	Cohort #2	Cohort #3	<i>M</i> ^a (<i>N</i> = 66)
	2014 (<i>n</i> = 16)	2015 (<i>n</i> = 18)	2016 (<i>n</i> = 32)	
Curriculum				
Attended workshop	7 (43.8)	12 (66.7)	18 (56.3)	37 (56.1)
Exhibited artwork	9 (56.3)	9 (50.0)	15 (46.9)	33 (50.0)
Attended exhibit	12 (75.0)	9 (50.0)	17 (53.1)	38 (57.6)
Future art ^b use				
Office décor	10 (62.5)	13 (72.2)	22 ^c (71.0)	45 ^d (69.2)
Stress relief	7 (43.8)	6 (33.3)	13 ^c (41.9)	26 ^d (40.0)

^aThe final column (*M*) is the mean percentage over all cohorts.

^bMore than one response permitted; top two responses ranked.

^c*n* = 31

^d*N* = 65

Students' comments—most of which were positive—express the value that the arts curriculum had for them.

"I still display my artwork in my room and will continue to do so for many years to come" (fourth-year medical student, Cohort #1).

"Many people did not see themselves as creative, and were frustrated and refused to see the value in such an assignment because they thought they would perform poorly. For this reason, I think it is a useful exercise, not just for the relevance of the medical humanities, but to force students to move outside of their comfort zone and be resilient which are skills vital to becoming a successful junior doctor" (fourth-year medical student, Cohort #1).

"I think its [sic] a fantastic inclusion to the program. Arts education in medicine helps to humanise science and connect medical education theory into a patient journey. The art also brought out other qualities the medical student possesses other than science. It [made] me realise how

creative and thoughtful some of my peers were and that deep down the really do think about and care about the patient's journey in medicine" (third-year medical student, Cohort #2).

"I spent a lot of time on it that could have been spent studying" (second-year medical student, Cohort #3).

"The art assignment made me remember why I decided to study medicine. It is easy to forget when all you do is study study study [sic]. The art assignment made me stop and reflect, resetting [sic] my drive to study to become a doctor not just for exams. Thank you" (second-year medical student, Cohort #3).

"Its [sic] easy to be blinded by the science part [of medical school] and forget the human part. So its [sic] good to have a well-balanced approach syllabus" (second-year medical student, Cohort #3).

The positive comments show students' general support for visual arts in the medical school curriculum. It is possible that some students will never find value in [medical humanities education](#) and view it as a distraction from their scientific studies. Although the purpose of medical education is said to be training students to form a "balanced judgment" about the data they encounter [29], it would be difficult to gain balance if students exclude their patients' humanistic data in favor of the "science." Including medical humanities education in medical school curricula is thus vital to the cultivation of balanced judgment.

Study limitations. Firstly, the low response rate (small sample size) is acknowledged. This is a common problem at our medical school, and steps are being taken to address it, as medical education research is valuable. Secondly, skills were self-reported by students rather than formally assessed, and self-reported data in the form of memories can be selective. Moreover, the three cohorts had taken the curriculum during different years. The 2016 cohort had a one-month reflective period that may have been too short for skills assessment and thus not readily comparable to the longer reflective periods of the other cohorts. Also, other aspects of medical education, in addition to visual arts exposure, could have influenced students' self-reported data about their reflective, listening, and observational skills.

Although the sample size of this study was too small to draw definitive conclusions, students who indicated that they had no involvement with the arts prior to enrolling in medical school (19.7 percent) generally had very low opinions of the arts curriculum when they were initially informed of it. It appears that exposure to the arts prior to medical school fosters receptiveness to arts education during medical school. By

contrast, students who have no arts exposure prior to medical school might not see the relevance of the arts to their education or medical practice.

Possible Application of the Bond University Medical Humanities Curriculum to Pathology

The Bond University medical humanities curriculum is currently delivered during education “blocks” focused on the immune, endocrine, and musculoskeletal systems; however, the medical humanities content has no direct link to the scientific content of the blocks. This was done to give students more freedom of artistic expression within their compulsory assignment. Another approach could be to directly link the medical humanities content with the scientific content. For example, an anatomy session could be co-taught with a [medical illustrator](#) experienced in drawing pathologies for books and journals. Another option would be to create a session that linked standard anatomical teaching with the history of medicine, using a medical historian to educate by way of famous paintings depicting pathologies [30-32].

Conclusion

This small study shows that arts education can be a “breath of fresh air,” a complement to the rigorous and stressful nature of the medical school curriculum. Overall, evidence from Australia and elsewhere shows numerous benefits of such education—especially the development of reflective thinking and observation skills—and students around the world overwhelmingly embrace it. Medical schools and accreditation bodies should support and encourage the inclusion of visual literacy training using the visual arts.

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