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Confidentiality

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FROM THE EDITOR
Defining the Limits of Confidentiality in the Patient-Physician Relationship

There is a growing need to redefine confidentiality for the twenty-first century. Illness and medical treatment can be deeply personal in nature, yet the scope and complexity of modern health care makes privacy of information difficult to achieve. Often, many parties—primary care clinicians, consulting physicians, managed care organizations, retail pharmacies, and health insurance companies—have access to an individual's health care information. Maintaining a patient's right to confidentiality amid this network can be quite challenging. As medical students and physicians, how should we help maintain patient confidentiality? Is it unreasonable to even expect confidentiality in modern medicine? Do electronic health records improve or threaten patient confidentiality? And, in cases of potential harm to self or others, when should a physician breach a patient's confidentiality? The answers to some of these are clear-cut and legally well defined, while others leave considerable room for interpretation and ethical decision making. This issue will explore these grey areas.

Confidentiality is a principal concern in relationships between patients and medical professionals and trainees, medical research and participant recruitment, and medical and pharmacy records. We begin our consideration of modern confidentiality by examining American physician and medical ethicist Mark Siegler's seminal 1982 essay in the *New England Journal of Medicine* entitled "Confidentiality in Medicine – A Decrepit Concept." In this influential article, Siegler critiqued the traditional formulation of confidentiality, arguing that "medical confidentiality, as it has traditionally been understood by patients and doctors, no longer exists" [1]. Indeed, the climate of medicine has continued to shift in the 30 years since Siegler first proffered his thesis. In this month's journal discussion, George L. Anesi, MD, MA, a resident at Massachusetts General Hospital in Boston, discusses Siegler's ideas and their relevance to contemporary health care, offering insights and pointing out weaknesses. In an ethics case commentary, Pablo Rodriguez del Pozo, MD, JD, PhD, an associate professor of ethics at Weill Medical College of Cornell University in Qatar, explores the dilemma of a physician treating an adolescent who wants to start on antidepressants without involving his parents.

The other case commentaries consider the concept of intraprofessional confidentiality. In one case, a third-year medical student with an eating disorder requires inpatient care. Georgette A. Dent, MD, associate dean for student affairs at the University of North Carolina School of Medicine, discusses how a medical school should best handle the situation, laying out specific guidelines for how to protect the student's confidentiality while supporting her education: seeking for her to receive care outside her home institution, abiding by Liaison Committee for

Medical Education standards, and addressing the break from education in the medical student performance evaluation (MSPE) for residency programs.

We ask whether there is implied intraprofessional confidentiality among medical professionals and trainees in a case in which a medical student who witnesses his attending physician's inappropriate behavior discusses it with other students. Peter A. Ubel, MD, the Madge and Dennis T. McLawhorn University Professor of Business, Public Policy and Medicine at Duke University, writes about the moral courage needed to confront bad role models. Robert M Veatch, PhD, an ethics professor at Georgetown University, differentiates patient confidentiality and confidentiality among professional colleagues and considers the moral grounds of the confidentiality duty.

Three contributions discuss confidentiality in as it pertains to records and data. This month's health law piece features the infrequently studied topic of postmortem confidentiality. Graduate students Courtney Mathews and Andreia Martinho review the legal precedents and AMA guidance concerning the permissibility of disclosing a deceased person's medical information, such as genetic disorders, research findings, and autopsy results. This month's excerpt from the American Medical Association's *Code of Medical Ethics* includes an opinion on confidentiality after death.

In the state of the art and science section, authors Laurinda B. Harman, PhD, RHIA, Cathy A. Flite, MEd, RHIA, and Kesa Bond, MHA, RHIA, PMP, of Temple University provide an excellent overview of the current priorities for making electronic health records (EHRs) ethically sound, including controlling access to maintain patients' confidentiality and maintaining data integrity and availability.

The policy forum piece by Barbara J. Evans, PhD, JD, LLM, director of the Center on Biotechnology & Law at the University of Houston Law Center, discusses a recent push to give patients property rights over their genetic information or health records in general. She compares the benefits and pitfalls of patient ownership of data to the current system and concludes that ownership rights may not be a "fruitful path for reform."

The final two pieces this month consider the very concept of confidentiality and its origins. In the medicine and society section, Sue E. Estroff, PhD, and Rebecca L. Walker, PhD, faculty at the University of North Carolina at Chapel Hill, contribute an elegant essay on the roots and implications of medical confidentiality broadly construed. In the history of medicine section, Angus H. Ferguson, MPhil, PhD, a scholar at the University of Glasgow, considers when exceptions to absolute medical confidentiality emerged and concludes that the boundaries of confidentiality have *never* been absolute.

It was a pleasure to work on this issue of *Virtual Mento*r. The topic of confidentiality is one that permeates virtually every aspect of medical training and practice, and I

am honored to have contributed to the exploration of many nuances of confidentiality and its ethical implications.

References

1. Siegler M. Confidentiality in medicine—a decrepit concept. *N Engl J Med*. 1982;307(24):1518-1521.

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ETHICS CASES
Repeating an Attending Physician's Unseemly Remarks
Commentary by Peter A. Ubel, MD, and Robert M. Veatch, PhD

Alex, a third-year medical student, is in the middle of his surgery rotation. He frequently finds himself rather shocked by some of the unseemly remarks that his attending, Dr. Tate, makes during surgery and between seeing patients on rounds. A highly respected surgeon, Dr. Tate is personable with patients and well liked by them, but his comments to his residents and medical students outside of patient earshot are often distasteful and inappropriate (e.g., "Sure I can fix his heart now but he'll croak before Christmas" or "It's hardly worth it to consent her—she's way too dimwitted to understand a thing" or "This patient was here in January and is so fat that she literally broke the bed"). The other med students also seem put off by this behavior, but no one has said anything to Dr. Tate.

Almost every day at lunch, Alex relates several of Dr. Tate's comments to his friends. Meg, another third-year on a different rotation, feels uncomfortable when Alex discloses these details. She pulls Alex aside after lunch one day and shares her concerns. "Alex, what happens on rounds or in the operating room is supposed to be kept confidential. I agree that Dr. Tate's comments are distasteful, but I don't think you should be gossiping to other students about him."

Alex scoffs, "There's nothing wrong with sharing an attending's comments as long as the *patient's* confidentiality is maintained."

Commentary 1
by Peter A. Ubel, MD
In the mid-90s I met Ari Silver-Isenstadt, a medical student who had been asked by his school to take a year off from his medical training to pursue a master's degree and, more importantly, to take a step back from what the school perceived to be his inappropriately confrontational behavior. While rotating through an affiliated hospital, you see, Ari had complained that the nametags provided to him by the hospital didn't properly identify him as a medical student, as if the hospital were trying to hide his amateur status from their patients. The hospital didn't take too kindly to his criticism. On a subsequent rotation through the ob/gyn clinic, Ari refused to "practice" a pelvic exam on an anesthetized woman because he wasn't sure anyone had asked her permission. That put an abrupt end to his rotation.

Ari's situation raises an important ethical question: When medical students witness, or are even asked to participate in, unseemly behavior, do they have a moral duty to

do something? Or instead, as Alex's case study forces us to ask: do they have a duty to remain silent, to protect patient and physician confidentiality?

Leaders at Ari's medical school felt that he should have remained quiet in the face of such modest ethical breaches and waited to address these problems when he was in a leadership role himself. Indeed, when I was a medical student, I sat in on a case conference once in which an oncologist stood up and explained to the audience that, although the patient's metastatic cancer was "incurable, the patient requested chemo anyway, so we offered him a cycle of salvage chemo. Unfortunately, the patient passed away the following week." I was stunned by what I considered to be an example of cruel overtreatment. So I stood up, my short white coat announcing to the rest of the audience my lowly status as a medical student, and asked how this oncologist could justify "torturing this patient in the last week of his life." After the conference ended, the chief medical resident pulled me aside and told me that, although he understood my point, I was only hurting my own career by confronting a senior physician in such a public manner.

No medical student should be expected to confront her superiors every time she encounters questionable behavior. Therefore, when Ari did choose to confront his faculty mentors, he was not responding to the call of moral duty. Instead, he was going beyond his duty—he was demonstrating moral courage. Where would our world be if no one took the risk of confronting powerful people when they believe those people are abusing their power?

What about Alex, then—the student in this case? Alex is not exhibiting morally courageous behavior by discussing Dr. Tate's behavior with his classmates. Instead, I expect that Alex's lunchtime conversations are an attempt to sort out his own moral and professional feelings. It is important for medical students to have these kinds of conversations. Medical students confront all kinds of morally questionable behavior during their training. They are exposed, as in Alex's case, to shocking and inappropriate humor. If they simply ignore these ethical breaches, they may become immune to them, thereby following suit when they become attending physicians. It is really important for medical students to talk, at a minimum with each other, about the moral questions they face in their work lives, so they can better think through how to behave in their own futures.

Do Alex's conversations violate some kind of intraprofessional confidentiality? No—Alex doesn't owe Dr. Tate any kind of confidentiality. Tate, on the other hand, owes it to Alex to act as a better role model.

The real ethical question here then is not whether Alex should be able to discuss his moral concerns with his classmates. It's whether Alex has a duty to go further, to act with moral courage and confront his superior. Confronting Tate head-on isn't the right course, however, if Alex doesn't think Dr. Tate would take such confrontation well. It probably won't change Tate's behavior, and will only end up hurting Alex.

It would be better instead for Alex to speak in confidence with the faculty member who organizes the surgery rotation for medical students. The confidentiality that matters in these discussions, by the way, is not any patient's confidentiality. Alex doesn't need to mention any patients by name in describing Tate's behavior, and he certainly doesn't have to protect Dr. Tate's confidentiality—in fact he needs to let people in power know that Dr. Tate is behaving this way. The confidentiality that matters here then is Alex's. He should be able to report Tate's behavior to the powers that be without suffering undue consequences.

The preceptor should promptly determine whether Alex's story holds up by interviewing students and others who work or have worked with Tate. If the story is substantiated, the preceptor should tell Tate that colleagues and supervisees "have witnessed inappropriate behavior" on his part and that if he doesn't improve his behavior, he will no longer be allowed to supervise medical students.

Peter A. Ubel, MD, is the Madge and Dennis T. McLawhorn University Professor of Business, Public Policy and Medicine at Duke University in Durham, North Carolina. His research explores controversial issues about the role of values and preferences in health care decision making, from decisions at the bedside to policy decisions. His books include *Pricing Life* (MIT Press, 2000) and *Free Market* (Harvard Business Press, 2009). His newest book, *Critical Decisions* (HarperCollins, 2012), explores the challenges of shared decision making between doctors and patients. Dr. Ubel's blog and other information about him are available at www.peterubel.com.

Commentary 2
by Robert M. Veatch, PhD

The norms of confidentiality have a long and confusing history. Although most assume that in the health care arena confidentiality has always prevailed, the reality is much more complex. Since the days of the Hippocratic Oath, the physician was asked to promise only to keep confidential "that which should not be spoken abroad" [1]. The obvious question is what should be spoken abroad. The traditional answer in Hippocratic ethics was surprising. The physician had a right (or even a duty) to disclose information that he believed would benefit the patient, even though the patient might object to the disclosure. By contrast, physicians were not supposed to speak abroad patient information for the benefit of third parties (threats to harm others or expose them to risk of a communicable disease).

The "Tarasoff" case (known by the name of the third-party victim) changed all of this. Health professionals were found to have a legal duty to warn potential victims of their patients' credible threats of harm [2]. More or less at the same time, moral agreement began to emerge that paternalistic disclosures for the patient's benefit but against his or her will were found no longer acceptable. The AMA, for example, changed its policy on confidentiality in 1980 [3].

In the present case, Alex's comments about the insensitive remarks of Dr. Tate give us the chance to add even more nuance to the confidentiality norms. I will argue that Alex is not subject to any professional norm that would limit transmission of his observations of his surgery instructor. To do so, I need to take up four issues: the distinction between patient confidentiality and confidentiality among professional colleagues, the moral grounds of the confidentiality duty, limits to the promise of confidentiality, and the source of the norms related to confidentiality.

Patient Confidentiality and Confidentiality between Health Professionals

The traditional norms of confidentiality govern patient information. They say nothing about information pertaining to colleagues or fellow members of the health professions. Thus, even if we can figure out what duty Alex and Dr. Tate have regarding patient information, this tells us little about Alex's disclosures of Dr. Tate's remarks. The norms of patient confidentiality exist for specific reasons—the physician's learning extensive information about the patient to facilitate the treatment and the inequality in the clinical relationship—and cannot be generalized to other relationships. These are quite different in the relation between student and instructor. Just as the norms of patient confidentiality do not tell us whether the patient has a duty to keep observations about his or her physician confidential, so they do not tell us whether there should be limits to a student's disclosing observations about an instructor.

That being said, it is striking that Dr. Tate's offhand comments, in fact, disclose quite a bit of patient information. The first comment discloses a bit about diagnosis and prognosis. The second comment discloses an assessment of patient intelligence. (It also reveals Dr. Tate's poor understanding of the concept of consent. Consent is not something a doctor does to a patient. It is an act of the patient. No health professional should ever talk of "consenting" someone.)

Moreover, when Alex repeats these comments he is disclosing patient information to his fellow student. The norms of patient confidentiality probably permit communication of patient information to colleagues and students when necessary to carry out professional duties, but should not be seen as permitting an unlimited exception to the duty of confidentiality when talking to professional colleagues. Meg did not need to know the patient's prognosis or intelligence; perhaps Alex did not need to know this either. In this case, Alex may not be able to keep the patients' identities from Meg, but even if he could the disclosure would still breach confidentiality. Even if Meg cannot identify the patient, Alex is still disclosing confidential information. Anonymizing information does not necessarily negate the confidentiality duty.

The Moral Grounds of the Confidentiality Duty

Let us assume that Dr. Tate's insensitive remarks did not actually disclose information about specific patients, but nevertheless did reveal an inappropriate attitude for a physician. What is Alex's duty regarding passing on such remarks? He would not be guided by patient confidentiality norms. Is there a similar duty of

confidentiality regarding information one has observed or remarks one has heard by a colleague? To answer this, we must ask upon what the various confidentiality obligations are grounded.

Sometimes people assume that confidentiality is grounded in the right to privacy. Privacy comes in two forms: informational privacy and observational privacy. Privacy is the state of not having personal information disclosed to others (the hacking of a computer to see someone's tax returns) or the state of not being observed by others (the peeping Tom). Whether one has a right to either form of privacy is a complicated issue. I probably have a moral right not to have my computer hacked, but not to have information I post on the public portion of my Facebook account kept private. I have a right not to have people look in the window of my home, but not to avoid having people observe me as I walk down the street.

An expectation of confidentiality arises when a promise—explicit or implicit—is made or a privacy norm is established by public policy. We don't promise people that their Facebook accounts will not be examined or that they won't be watched walking down the street. We do not have a general right of confidentiality, only a right established by promise or policy. The traditional Hippocratic Oath apparently did not promise patients a right not to have their information disclosed if their physicians decided the disclosure would further their best interest. It did, however, promise that patient information would not be disclosed to third parties even when those third parties were at risk of serious injury from the patient. In the final decades of the twentieth century we renegotiated those promises so that paternalistic disclosures were no longer acceptable, but certain disclosures to protect third parties were acceptable, that is, physicians no longer promised to keep patient information confidential if disclosure would protect third parties from serious injury. At least physicians should no longer make such promises. They would violate the law if they kept such promises. Hence, posting the World Medical Association's Declaration of Geneva on the waiting room wall (which promises confidentiality without the third-party exception) would, in effect, be promising to break American law if the Tarasoff situation arose.

The Limits to the Promise of Confidentiality

Now the question for Alex is whether he promised not to reveal what Dr. Tate said. Presumably, he has at least implied a promise not to reveal patient information so the patient-relevant pieces of Dr. Tate's remarks should not be disclosed. There is no reason to believe, however, that Alex has ever promised to refrain from disclosing the information and observations about his instructor. In fact, such a promise would run afoul of the medical profession's norms of self-regulation, in which colleagues who observe inappropriate or dangerous behaviors in their fellow workers—a surgeon who operated while intoxicated, for example—are sometimes considered morally required to disclose that information.

It seems clear that Alex has not made a blanket promise of confidentiality regarding information and observations about fellow students or professionals. If he has made

such a promise, it was a moral mistake. We must reserve the right to speak up in cases in which a colleague's behavior is inappropriate. In fact, we should also place some limits on the promise we make to patients, reserving the right to speak—perhaps the duty to speak—if a patient's behavior poses a serious risk of harm to others. I once felt forced morally to support a breach of confidentiality regarding a research subject when the data contained convincing evidence that the subject had committed a homicide.

Alex's case is more complex. He surely has the right to report his instructor to appropriate authorities if he believes Dr. Tate's attitudes and behavior vis-a-vis patients are clearly wrong. More generally, if Alex has not made any promise to keep his knowledge of Dr. Tate's attitudes confidential, he is not bound by a duty. He might, for example, be perplexed about what he should do regarding Dr. Tate and want an informal consultation with a fellow student about an appropriate strategy, and revealing it would be acceptable.

That being said, there are norms of discretion about what we say about any friend or associate's observed behavior. As a medical student Alex should be learning to exercise such discretion, not becoming a busybody who repeats observations about friends or colleagues just for the fun of it or as a sort of social capital. Nevertheless, he has no duty to refrain from transmitting Dr. Tate's comments except for the patient-revealing elements. If he is conscientiously pursuing an action to begin the review of Dr. Tate's disposition and whether he is an appropriate clinician-instructor, Alex may, in fact, have a duty to transmit.

The Source of the Confidentiality Norm or Promise

If, in fact, Alex's obligation is governed by social norms and promises made, we should pay attention to the source of these norms and promises. If they are presently ambiguous, as they appear to be, we should ask who should make them clearer. Traditionally, we believed that the profession had the responsibility to generate or articulate norms for professional conduct. Thus, the AMA was widely considered authoritative and could have spoken more explicitly on what physicians and medical students ought to be able to transmit when they observe a colleague's suspect attitudes or behavior.

Since the 1970s, however, we have questioned the legitimacy of the professional organization's authority to establish norms for professional conduct, at least as that conduct impacts nonprofessionals such as patients. We now generally hold that the broader social policy has this responsibility [4, 5]. Secular society or religious institutions are more appropriate bodies to articulate the moral norms of human conduct, including conduct between professionals and lay people. The wise former executive vice president of the AMA, James Todd, understood this when, in the report of the committee he chaired in 1979, he said, "The profession does not exist for itself, it exists for a purpose, and increasingly that purpose will be defined by society" [6].

Thus, my conclusion is that there is no clearly established duty of confidentiality among professional colleagues or medical students beyond the usual norms of discretion among acquaintances and, in fact, there is sometimes a duty to disclose the inappropriate behaviors of colleagues. If more explicit confidentiality promises among medical professionals are to be developed, the lay community should participate fully. That is what is called for if future patients are to be protected from professionals insensitive to patient rights, including the right to be respected.

References

1. Edelstein L. The Hippocratic Oath: text, translation and interpretation. In: Temkin O, Temkin CL, eds. *Ancient Medicine: Selected Papers of Ludwig Edelstein*. Baltimore, MD: The Johns Hopkins Press; 1967:6.
2. *Tarasoff v Regents of University of California*. 17 Cal 3d 425, 131 Cal Rptr 14, 551 P2d 334.
3. American Medical Association. Principles of medical ethics. In: *Current Opinions of the Judicial Council of the American Medical Association*. Chicago: American Medical Association; 1981:ix.
4. Veatch RM. *A Theory of Medical Ethics*. New York: Basic Books; 1981.
5. Veatch RM. *Hippocratic, Religious, and Secular Medical Ethics: The Points of Conflict*. Washington, DC: Georgetown University Press; in press.
6. Todd JS. Report of the Ad Hoc Committee on the Principles of Medical Ethics [of the American Medical Association]. Unpublished report; 1979.

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ETHICS CASES
Confidential Mental Health Treatment for Adolescents
Commentary by Pablo Rodriguez del Pozo, MD, JD, PhD

Dylan is a bright 16-year-old student who has depression, which he discussed during his last appointment with his longtime family physician, Dr. Emory. Dylan's parents divorced a year and a half ago and Dylan has been struggling to adapt to the change in living situation.

During his annual sports physical, Dylan reveals that he has started having thoughts of cutting himself. He feels that his depression has gotten worse and admits to "checking out web sites" about cutting or otherwise harming himself. When Dr. Emory questions him further, Dylan just shrugs and seems noncommittal about what he means by hurting himself. He even says that he "won't actually do it."

Dylan wants a prescription for an antidepressant but begs Dr. Emory not to tell his mother, who is in the waiting room. Dr. Emory counsels Dylan that depression and thoughts of cutting himself are serious issues and recommends involving a therapist and the support of his parents. Dylan is very much against this idea.

Dr. Emory believes that a low-dose antidepressant will help Dylan but is uncomfortable with writing the prescription without, at the very least, frequent follow-ups to monitor Dylan's depression and thoughts of self-injury. Yet Dylan is reluctant to agree to another appointment in two weeks. "I can't tell my mom I have to come back again so soon!"

As their family physician, Dr. Emory knows that Dylan's parents are divorced and share custody of Dylan and his younger sister. He also knows that Dylan is close to his grandma across town. He asks Dylan if he would be willing to involve his grandma, as someone to support him and drive him to appointments. Dylan seems more open to the idea, but still would rather just start on an antidepressant without telling anyone.

Dr. Emory has a good rapport with Dylan but thinks he probably needs more help and support than he can offer, especially since Dylan is unlikely to follow up on his own.

Commentary
Complex forces pulling in opposing directions define this case involving a teenager visited by thoughts of cutting himself. The patient, Dylan, is a young man in the throes of adolescence and divorce—and, perhaps, depression. The physician, Dr. Emory, is torn and may not be entirely comfortable with whatever decision he makes.

To begin with what we know and don't know: Dylan is a bright teenager whose parents divorced 18 months ago. He is depressed and has had self-destructive thoughts. The vignette does not provide detailed information about, or a clear timeline of, Dylan's symptoms of depression. During a previous visit, Dylan had mentioned he was feeling blue. But Dr. Emory knows that the teenager is struggling to come to grips with his new family dynamics. It is unsurprising that Dylan is not cheerful. In this most recent visit, Dylan asks to be put on antidepressants and mentions that he wants to cut himself—though he clarifies he's unlikely to actually do it.

Dr. Emory's Dilemma
Teenage depression is an elusive diagnosis: adolescence is a phase of life marked by mood swings that can last from hours to days to months. Dylan's clinical condition is far from clear-cut, and in my view Dr. Emory's first dilemma is not ethical but rather clinical. Dr. Emory can't medically pronounce Dylan to be depressed based solely on the feelings that the young man expresses on two occasions. And yet he can't rule out a diagnosis of depression, either.

Dr. Emory thus faces a clinical dilemma which presents a second, now moral dilemma.

Underage patients enjoy in most states in the U.S. an *ad hoc* legal capacity to consent by themselves to certain medical services, such as those related to reproductive health, substance abuse and—as in Dylan's case—outpatient mental health. The purpose of this exception to the rule of capacity is to protect the confidentiality of patient information. Otherwise, the fear of disclosure would prompt minors to forgo health care services, risking their health and sometimes that of others. Dylan can consent to outpatient mental health care and has the right to do so confidentially [1, 2].

However, this *ad hoc* capacity and the confidentiality attached to it cannot go beyond the reason they are granted in the first place, namely to protect the health of minors. State legislation thus authorizes doctors to disclose information if confidentiality poses a risk to the health of the minor or others.

That means that if Dr. Emory hastily decides that Dylan suffers from depression and is at risk of suicide, and Dylan is actually neither, the doctor would be breaking his duty of confidentiality unjustifiably, since this diagnosis (most particularly if

followed by treatment with antidepressants) would almost certainly entail his informing Dylan's parents. Dr. Emory knows that premature disclosure would destroy Dylan's trust in him and make Dylan even more resentful of the adult world at a time when he's in particular need of adults to confide in.

But if Dr. Emory does not pronounce Dylan depressed and suicidal and Dylan turns out to be both, he would be preserving confidentiality at the unjustifiable price of putting his young patient at risk.

Dr. Emory must not fail Dylan in either way. The clinical dilemma poses an ethical dilemma—yet another reminder that clinical judgment and ethical judgment are inseparably interwoven in the doctor's office [3]. And Dr. Emory needs to make a decision now, while Dylan is sitting in his office and his unsuspecting mother is waiting outside.

The goals of Dr. Emory's intervention at this point should be to arrive at a precise diagnosis by referring Dylan to a specialist, who may start the teenager on counseling and psychotherapy. Time is critical here, but Dr. Emory has the chance to buy additional time by combining an appealing plan with a gentle push.

Adult Supervision

This is where Grandma comes in. Dylan is open to the idea of involving his grandmother, with whom he has a close relationship. Involving Grandma seems like a good option for Dylan, but is it legal to involve her instead of his parents?

Given the outpatient mental health nature of the services required, Dylan has the right to conceal his clinical information from his parents. The right to exclude everyone implies, at the same time, that Dylan has the right to have that information selectively disclosed to a trusted adult, in this case his grandmother. Grandma would not become, though, Dylan's representative *in loco parentis*. She would simply be someone with whom Dylan has decided to share otherwise confidential medical information. Involving Grandma does not imply that Dylan waives his right to consent or to confidentiality, and he should be made aware of this.

His grandmother will not only drive Dylan to appointments for further evaluation and perhaps psychotherapy sessions, but she also will be in a position to monitor his progress, help with compliance, and be the friendly, protective listener that Dylan's situation seems to cry out for. In addition, she may be able to help Dylan gauge how much information his parents will receive. She can be a big help to Dr. Emory—and Dylan—in deciding if and when the parents need to get involved.

Now for the issue of antidepressants. Dylan is requesting that he be started on antidepressants without letting anyone know. Dr. Emory has here the chance to turn Dylan's request into a gentle nudge towards the plan he's proposing.

Antidepressants hardly seem to be an option at this point. First and foremost, Dylan's diagnosis is still not clear. Even if it were, antidepressants "may increase suicidal thoughts or actions in some children, teenagers, and young adults when the medicine is first started," the FDA warns [4]. Dr. Emory should educate Dylan about the indications and risks of antidepressants. These drugs call not only for medical follow-up, but essentially for family awareness and close monitoring—which Dylan has ruled out. Dylan should understand that nondrug treatments are probably safer and more effective [5, 6] with the added benefit that they require no disclosure.

This is one of those instances where doctors have the duty to use their power for the benefit of the patient [7]. Dr. Emory is in the position to stress to Dylan that that if he were started on antidepressants now, he would need to involve his parents. After proper evaluation and waiting to see whether Grandma's support and monitoring seem strong, Dr. Emory could consider antidepressants without disclosure. However, Dr. Emory would do well to work together with Dylan and his grandmother to bring his parents on board before others—insurers or social networking or a school official—do it for them.

Maintaining Confidentiality

There is always the strong possibility that the insurance company will tip off Dylan's parents. It is safe to assume that Dylan is covered by his parents' health insurance, and they might at some point receive information revealing Dylan's medical activities.

Under HIPAA regulations, Dylan can request that all communications to him from Dr. Emory's office and from the health plan are made confidentially by e-mail or a phone that is not shared with his parents. However, laws and regulations on this point are open to interpretation. In addition, billing and administrative information sent by the insurer is likely to leave Dylan in the open. On the other hand, information regulated by the Family Educational Rights and Privacy Act (FERPA) is exempt from HIPAA protection. This means that if medical information about Dylan's mental care reaches his school for any reason, Dylan's parents will have the right to access it as they have the right to access their son's grades [8].

Last but not least, Dylan may undermine his own confidentiality. Adolescents and young adults e-mail, text, and Tweet themselves to thumb tenosynovitis [9] and addictively use Facebook [10]. It would surprise no one if information shared on social networking web sites somehow reached Dylan's parents.

Concluding Remarks

Dylan's case illustrates the ethical component inherent in clinical judgment. Of course the clinical facts must be clearly understood to make sound clinical judgment; technical competence is thus the first virtue of a good doctor. But when a situation is clinically problematic, it is often morally problematic as a corollary. Dr. Emory must determine what is best for his patient in the broadest sense.

Determining the clinical facts may be constrained by nonclinical aspects of the case. And the final goals of medical care [11] are not limited to instituting a treatment, but also encompass helping put in place a context that will enable it to work. Clinical practice does not happen *in vitro.*

Dylan's case also exposes how patients frequently have unrealistic expectations about the efficacy of medications and a complete ignorance of their risks. Doctors need to educate their patients on those benefits and risks.

The story affords us the opportunity to think about the limitations of the principles of autonomy and self determination in the case of minors. The last 30 years in medical ethics have been marked by the rise of those principles. In the case of minors, doctors are morally obliged to use their authority. However, such use may backfire if it is not applied in conjunction with educating young patients of the risks and benefits of the options.

Autonomy and confidentiality are granted to the underaged for the sole purpose of protecting their health but cannot be invoked when doing so would compromise that very specific purpose. It is a doctor's duty to draw the line, the heaviest and most delicate task Dr. Emory has on his shoulders.

The case, finally, reminds us that in a hyperconnected world, confidentiality may prove short-lived. And if confidentiality can't be guaranteed, protecting the health of adolescents may become an increasingly difficult enterprise.

References

1. Boonstra H, Nash E. Minors and the right to consent to health care. *Issues Brief (Alan Guttmacher Inst)*. 2000;(2):1-6.
2. Lehrer JA, Pantell R, Tebb K, Shafer MA. Forgone health care among U.S. adolescents: associations between risk characteristics and confidentiality concern. *J Adolesc Health*. 2007;40(3):218-226.
3. Montgomery, K. *How Doctors Think: Clinical Judgment and the Practice of Medicine*. New York: Oxford University Press; 2005:49.
4. US Food and Drug Administration. Medication guide: antidepressant medicines, depression and other serious mental illnesses, and suicidal thoughts or actions. http://www.fda.gov/downloads/Drugs/DrugSafety/InformationbyDrugClass/ucm100211.pdf. Accessed June 3, 2012.
5. Jureidini JN, Doecke CJ, Mansfield PR, Haby MM, Menkes DB, Tonkin AL. Efficacy and safety of antidepressants for children and adolescents. *BMJ*. 2004;328(7444):879-883.
6. Tonkin A, Jureidini J. Wishful thinking: antidepressant drugs in childhood depression. *Br J Psychiatry*. 2005;187:304-305.
7. Brody H. *The Healer's Power*. New Haven, CT: Yale University Press; 1993.

8. English A, Ford CA. The HIPAA privacy rule and adolescents: legal questions and clinical challenges. *Perspect Sex Reprod Health*. 2004;36(2):80-86.
9. Williams IW, Kennedy BS. Texting tendinitis in a teenager. *J Fam Pract*. 2011;60(2):66-67.
10. Andreassen CS, Torsheim T, Brunborg GS, Pallesen S. Development of a Facebook Addiction Scale. *Psychol Rep*. 2012;110(2):501-517.
11. Fins JJ, Miller FG. Clinical pragmatism, ethics consultation, and the elderly patient. *Clin Geriatr Med*. 2000;16(1):71-81, ix.

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ETHICS CASES
The Student Becomes the Patient
Commentary by Georgette A. Dent, MD

Kathryn is a medical student who struggled with an eating disorder throughout high school. She was hospitalized for 6 weeks during her sophomore year and then worked with a therapist on an outpatient basis for 2 years. By the time she reached college, she was at a stable, healthy weight and had developed coping strategies for her underlying control and anxiety issues. She excelled as an undergraduate and was accepted into her first-choice medical school. She did very well during her first 2 years, breezing through most of the preclinical curriculum while maintaining healthy eating and exercise habits.

Now in her third year, Kathryn has found that the stress of clinical rotations is taking its toll. She has fallen back into old habits of restrictive eating and overexercising. When she visited her parents during winter break, they were shocked by her significant weight loss and obvious distress and confronted her with their concerns. Kathryn admitted she was terrified at the prospect of gaining the 30 pounds necessary to reach a normal weight. Eventually, she agreed that she needed help and expressed a desire "to be done with this whole eating disorder once and for all."

Kathryn was waiting in front of the student affairs dean's office on the first Monday morning after winter break. The dean was startled by Kathryn's baggy clothing, sunken cheeks, and dark circles. Kathryn looked nervous but spoke matter-of-factly. "I need to talk to you," she began. "My parents and I have decided that I need inpatient care, and I don't know what that means for my rotations." She looked at the ground. "And can we please keep this as confidential as possible? I don't want people finding out."

Commentary
Medical school can be an intense and stressful experience, and medical students are vulnerable to psychiatric disorders. The paramount concern of the student affairs dean in this example is promoting the student's health, followed by protecting her privacy and supporting her medical education.

Student affairs deans play multiple roles in medical schools, representing students, the institution, and the medical profession. As the student's advocate and often counselor and confidant, the dean should support the student in getting access to mental health care in a manner that protects her privacy. As an institutional representative, the dean should make sure that laws, such as the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA), are followed and that the school complies with

accreditation standards set by the Liaison Committee on Medical Education (LCME). As a representative of the profession, the student affairs dean should make sure that there is appropriate documentation of the student's record in the medical student performance evaluation (MSPE) that will become part of her residency application.

The Student's Health

Medical schools should have protocols in place to ensure that their students get mental health care in a timely and confidential fashion. LCME Standard MS-27 stipulates that "a medical education program must provide medical students with access to diagnostic, preventive, and therapeutic health services." The standard's annotation specifies that "a medical education program should have policies and/or practices that permit students to be excused from class or clinical activities to seek needed care" [1]. The best option would be for Kathryn to be hospitalized at an institution not affiliated with her medical school. The medical school should have a policy or practice to ensure this. To address Kathryn's concern about her rotations, the dean should explain that she will be allowed to take a leave of absence and return to the curriculum when her health is better. The leave of absence is discussed in more detail below.

The Student's Privacy

If Kathryn is hospitalized at an outside institution, her privacy is preserved because only the student affairs dean is aware of her situation. While obtaining care at an outside institution is preferable, sometimes this is not feasible because of the acuteness of the student's condition or because the treatment needed is only available at the student's home institution. If it is not feasible to refer Kathryn to an institution unaffiliated with her medical school and she is hospitalized at her home institution, then the student affairs dean must take careful steps to ensure that Health Insurance Portability and Accountability Act and Family Educational Rights and Privacy Act requirements are followed. During treatment, Kathryn should not be exposed to her student peers. Additional privacy concerns related to the student's return to the curriculum are mentioned below.

The Student's Education

Leave of absence. One of the admirable aspects of this case is the fact that the student came forward of her own accord. Physicians and medical students must have the insight to remove themselves from the care of patients, or in the case of students, from their coursework, if they have a condition that prevents them from performing competently. At the University of North Carolina School of Medicine, students sign a technical standards agreement prior to matriculation that stresses the importance of mental fitness, acknowledging that, while students with psychiatric conditions may be successful, "it is essential that a medical student be willing to acknowledge the disability and accept professional help before the condition poses danger to self, patients, or colleagues" [2].

When students proactively identify their needs before their condition has had a negative impact on their performance, in many medical schools they will have the

option of choosing to take a personal leave of absence. On the other hand, if the student's condition has resulted in poor academic performance or a lapse in professionalism, then the student would most likely be remanded to the school's student promotions or progress committee and either placed on a medical leave of absence or dismissed.

Return to the curriculum. The conditions under which Kathryn may return to the curriculum will be determined by her leave status. If allowed to take a personal leave of absence, her requirements for returning might be minimal. On the other hand, if she had been placed on a medical leave of absence, in many medical schools she would have to be examined by a mental health professional in contact with her primary psychiatrist, psychologist, or therapist to determine if and when she was healthy enough to return and outline any necessary follow-up treatment. When Kathryn returns to the curriculum, the student affairs dean would work with the clerkship directors to see that she is allowed to keep necessary treatment appointments without penalty while still meeting course and clerkship objectives.

If Kathryn had been hospitalized at an institution affiliated with her medical school and had not yet completed her psychiatry clerkship, then ideally she should be assigned for that clerkship to another institution. If she must complete her psychiatric clerkship at the same hospital at which she was a patient, at a minimum she must not be assigned to the eating disorders unit.

In accordance with LCME standard MS-27-A, "the health professionals at a medical education program who provide psychiatric/psychological counseling or other sensitive health services to a medical student must have no involvement in the academic assessment or promotion of the medical student receiving those services" [1]. Faculty members or residents involved in her care must not later be in a position to evaluate her. The Department of Psychiatry at UNC has a policy that states that residents cannot grade or evaluate students who have been their patients. In the event that the student must complete her psychiatry clerkship at her home institution, the student affairs dean would work to make sure the Department of Psychiatry policy was followed.

Residency applications. Another important consideration in this case is how Kathryn's illness and treatment should be handled in her medical student performance evaluation (MSPE or dean's letter), which depends on whether or not her mental health had an impact on her performance. If there was no impact on her performance, the MSPE would say that she chose to take a personal leave of absence. Depending on the student's specialty choice, she might be advised to address the leave of absence in her personal statement, perhaps pointing out that coping with her illness has given her additional insight into the experience of being a patient and should make her a better physician. She could also reassure residency program directors that the insight she gained from her treatment improved her ability to self-monitor her condition so that it will not compromise her ability to fulfill her responsibilities as an intern and resident. Our students have had good results in the

National Residency Matching Program by being candid in their personal statements about the challenges they have faced as medical students.

On the other hand, if the student had academic or professionalism problems that resulted in action by the student promotions or progress committee, then the MSPE would state that she was placed on a medical leave of absence to address the problems leading to those troubles. In this situation, it would be essential for the student to use her personal statement to give context to her situation.

Conclusion

In this scenario, the student approaches the student affairs dean with a very immediate need. The top priorities in such a situation are to identify the most appropriate treatment option for the student, to reassure her that she is doing the right thing by seeking treatment and that her confidentiality will be protected, and to address her questions about the impact treatment would have on her clerkships. Medical students should be able to access mental health care and maintain their privacy. Medical schools should treat students with psychiatric illnesses in a way that models how they would like to see students treat their future patients. Treating medical students who have psychiatric illnesses with compassion and sensitivity is the right and ethical thing to do, if medical schools seek to produce compassionate and sensitive physicians.

References

1. Liaison Committee on Medical Education. Functions and structure of a medical school: standards for accreditation of medical education programs; May 2011. http://www.lcme.org/functions.pdf. Accessed June 27, 2012.
2. University of North Carolina School of Medicine. Responsibilities of medical students. http://www.med.unc.edu/md/governance/policies/files/Article5ResponsibilitiesofMedicalStudents2012220.pdf. Accessed August 9, 2012.

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THE CODE SAYS
The AMA *Code of Medical Ethics*' Opinions on Confidentiality of Patient Information

Opinion 5.05 - Confidentiality
The information disclosed to a physician by a patient should be held in confidence. The patient should feel free to make a full disclosure of information to the physician in order that the physician may most effectively provide needed services. The patient should be able to make this disclosure with the knowledge that the physician will respect the confidential nature of the communication. The physician should not reveal confidential information without the express consent of the patient, subject to certain exceptions which are ethically justified because of overriding considerations.

When a patient threatens to inflict serious physical harm to another person or to him or herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, which may include notification of law enforcement authorities.

When the disclosure of confidential information is required by law or court order, physicians generally should notify the patient. Physicians should disclose the minimal information required by law, advocate for the protection of confidential information and, if appropriate, seek a change in the law.

Based on the report "Opinion E-5.05, 'Confidentiality,' Amendment," adopted November 2006.

Opinion 5.055 - Confidential Care for Minors
Physicians who treat minors have an ethical duty to promote the autonomy of minor patients by involving them in the medical decision-making process to a degree commensurate with their abilities.

When minors request confidential services, physicians should encourage them to involve their parents. This includes making efforts to obtain the minor's reasons for not involving their parents and correcting misconceptions that may be motivating their objections.

Where the law does not require otherwise, physicians should permit a competent minor to consent to medical care and should not notify parents without the patient's consent. Depending on the seriousness of the decision, competence may be evaluated by physicians for most minors. When necessary, experts in adolescent medicine or

child psychological development should be consulted. Use of the courts for competence determinations should be made only as a last resort.

When an immature minor requests contraceptive services, pregnancy-related care (including pregnancy testing, prenatal and postnatal care, and delivery services), or treatment for sexually transmitted disease, drug and alcohol abuse, or mental illness, physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient. Physicians should encourage parental involvement in these situations. However, if the minor continues to object, his or her wishes ordinarily should be respected. If the physician is uncomfortable with providing services without parental involvement, and alternative confidential services are available, the minor may be referred to those services. In cases when the physician believes that without parental involvement and guidance, the minor will face a serious health threat, and there is reason to believe that the parents will be helpful and understanding, disclosing the problem to the parents is ethically justified. When the physician does breach confidentiality to the parents, he or she must discuss the reasons for the breach with the minor prior to the disclosure.

For minors who are mature enough to be unaccompanied by their parents for their examination, confidentiality of information disclosed during an exam, interview, or in counseling should be maintained. Such information may be disclosed to parents when the patient consents to disclosure. Confidentiality may be justifiably breached in situations for which confidentiality for adults may be breached, according to Opinion 5.05, "Confidentiality." In addition, confidentiality for immature minors may be ethically breached when necessary to enable the parent to make an informed decision about treatment for the minor or when such a breach is necessary to avert serious harm to the minor.

Issued June 1994 based on the report "Confidential Care for Minors"; updated June 1996.

Opinion 5.051 - Confidentiality of Medical Information Postmortem
All medically related confidences disclosed by a patient to a physician and information contained within a deceased patient's medical record, including information entered postmortem, should be kept confidential to the greatest possible degree. However, the obligation to safeguard patient confidences is subject to certain exceptions that are ethically and legally justifiable because of overriding societal considerations (Opinion 5.05, "Confidentiality"). At their strongest, confidentiality protections after death would be equal to those in force during a patient's life. Thus, if information about a patient may be ethically disclosed during life, it likewise may be disclosed after the patient has died.

Disclosure of medical information postmortem for research and educational purposes is appropriate as long as confidentiality is maintained to the greatest possible degree by removing any individual identifiers. Otherwise, in determining whether to

disclose identified information after the death of a patient, physicians should consider the following factors:

(1) The imminence of harm to identifiable individuals or the public health
(2) The potential benefit to at-risk individuals or the public health (e.g., if a communicable or inherited disease is preventable or treatable)
(3) Any statement or directive made by the patient regarding postmortem disclosure
(4) The impact disclosure may have on the reputation of the deceased patient
(5) Personal gain for the physician that may unduly influence professional obligations of confidentiality

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.

Issued December 2000 based on the report "Confidentiality of Medical Information Postmortem"; updated December 2001.

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JOURNAL DISCUSSION
The "Decrepit Concept" of Confidentiality, 30 Years Later
George L. Anesi, MD, MA

Siegler M. Confidentiality in medicine—a decrepit concept. *N Engl J Med.* 1982;307(24):1518-1521.

In his influential 1982 essay [1], Chicago physician-ethicist Mark Siegler attempts to open the eyes of physicians and patients to the fact that patient confidentiality, as it has been taught since the times of Hippocrates, is dead.

He relays the case of a patient who, having been admitted to the hospital for a simple cholecystectomy, had between 15 and 100 hospital staff and students peering regularly, and with professional justification, at his medical record. This was 30 years ago; anyone recently in an American academic teaching hospital would say these numbers are far higher today due to any number of factors, including the move towards sub-subspecialization in medicine, ever-expanding support services (e.g., diabetes education program, tobacco cessation service, etc.), and resident work-hour restrictions (requiring more handoffs between clinicians).

Despite the need for this access—for clinical care, hospital administration, and teaching—Siegler's patient in the anecdote believes, in his gallbladderless gut, that his confidentiality has been breached. This breach is not in the traditional sense of a physician revealing information told in confidence to someone other than the patient outside of that pact, but a sense that, justified as it may be, a hospital chart read by 100 different people is by definition *not* confidential.

Siegler notes the conflict this creates between a patient's desire for confidentiality and his or her desire for the best care, which is often provided in highly staffed teaching hospitals and in an economically complex manner that requires the participation of additional nonmedical hospital staff (e.g., compliance officers and chart auditors). This desired advancement in patients' care, Siegler notes, comes at the expense of their eroding privacy—or at least requires a fundamental reworking of our understanding of it.

Siegler advocates a "need-to-know" approach in which only hospital staff who specifically need access would have it (despite previously noting that all 100 staff who viewed his patient's chart were "justified" in doing so). He proposes divisions of the medical record—e.g., medical, financial—for which access would be specifically granted or denied based on the need to know, but rejects the idea of wholly *separate* records for treatments like psychiatric care; this, he believes, would

lead to clinically inferior care and is not logistically possible for many specialties. He favors more explicit explanation to patients of what "confidentiality" actually means in a teaching hospital. And finally, he proposes patient access and veto power, so that patients could designate certain portions of the record to be viewed only by their "principal physician" or a specific list of other clinicians.

Discussion

Siegler's essay, now celebrating its thirtieth anniversary, contains both insights and inaccuracies, some due to its age and some independent of time.

It is entirely correct that the traditional *essence* or *notion* of patient confidentiality meant that personal information would only be shared with one's own physician and a short list of necessary collaborators, but it does not follow that the present-day idea of confidentiality encompassing a larger circle of participants is invalid. While this larger circle may challenge the "letter" of respect for the patient's sense of individuality and privacy, it is entirely consistent with the "spirit" of patient confidentiality. Certainly, clinicians not specifically involved in the care of a particular patient should not have access to his or her record. People either "need to know" because they have been brought into the patient's care, or they do not need to know and should not have access.

Medical students pose a particular concern. Assuming for a moment that students are definitively *not* contributing to the health care team (and are merely learning from the experience), then surely they must never qualify as "need-to-know." Similar arguments could be made about interns, then residents, and then perhaps even fellows, all of who have access to the record in part for training and do not have the experience of senior physicians. We generally allow them access, however, on utilitarian and perhaps justice-oriented grounds: all patients benefit from previous generations having allowed trainees to learn from them, and in turn today's patients must repay that debt, doing what is best for society overall, as long as harm to them is minimized by proper supervision.

Partitioning the Record

Regarding Siegler's proposal to divide, but not separate, the medical record, it is difficult to see a practical difference. A medical record can be divided into an unlimited number of discrete sections according to unlimited criteria; continually deciding which members of the hospital staff should have access to each section would not be reasonably possible. It would also be likely to work against the interests of the patient by preventing clinicians from fully understanding his or her condition. Siegler recognizes this problem in the context of separate psychiatric records ("it is often vitally important for internists or surgeons to know that a patient is being seen by a psychiatrist or taking a particular medication" [2]) but seems not to acknowledge that the same will occur if we call these "divisions" within a single record rather than "separate" records.

Electronic health records complicate the debate, both by offering intriguing options for more easily subdividing the medical record (which may seem to help Siegler's argument) and by generating far more data and methods of sorting it, expanding the number of possible "sections" exponentially. Likewise, it makes peering into the chart far easier because the viewer does not have to be physically on the ward with the paper chart, but also makes tracking who does the viewing far easier. Whether electronic health records push us towards or away from confidentiality is yet to be determined.

Finally, the idea that patients should bear the burden of deciding which pieces of their medical information should be viewed by whom seems both cruel and impossible. The idea of picking a single "principal physician" to have sole access to the complete medical record is incompatible with the way medicine is practiced today, and may very well have been so in 1982. Is this principal physician the attending of record (who often rotates every week or two at teaching hospitals), the primary care doctor (who less and less frequently participates in inpatient hospital care), or the intern (who spends the most time with the patient but is less experienced and now is required to go off duty every 16 hours)?

Patient Access to the Record

It is presently entirely accepted that patients may have access to their medical records in some form [3]. The specifics of that right are more complicated [4]. While there is a fundamental right for patients to know their diagnoses and prognoses and what interventions they undergo, clinicians also have a right—and a clinical necessity—to think more freely about diagnoses than would be responsible to reveal routinely with patients. When, for example, a patient has, among other symptoms, fevers and malaise, malignancy must always be considered in addition to more common, less grave diagnoses. What purpose would it serve for clinicians to routinely tell patients they are considering malignancy when they are merely being thorough by ruling out an extremely unlikely possibility?

Furthermore, clinicians in general and physicians in particular have a language of their own that is difficult if not impossible for even highly educated nonphysicians to decipher; errors in interpretation, some dangerous, can occur without guidance [5]. It follows that providing patients a verbatim copy of their medical records would be a violation of both nonmaleficence and the right of clinicians to have a private place for their thoughts. A solution in many locations has been a distilled version of the medical record given to patients on demand that aims not to hide information but instead to present it in a useful and, from a practical standpoint, equally complete form for the patient [6].

Conclusion

Modern medicine has in some ways, as Siegler argues, abandoned the kind of confidentiality based on privacy. It has also greatly advanced the equally important principle of beneficence. Certainly we should aim to keep those who do not need to know out of the chart and place safeguards to avoid related abuses, but a further

sectioning of the medical record seems an unlikely if not impossible solution. More effective will be communicating with patients about their expectations for different *forms* of confidentiality and privacy in different health care settings to facilitate informed decisions. Surely, patients are well situated to decide between coming to an academic center and a private community hospital but not, especially, to decide which consultants should know that they carry a psychiatric diagnosis for which they are prescribed medication.

References

1. Siegler M. Confidentiality in medicine – a decrepit concept. *N Engl J Med*. 1982;307(24):1518-1521.
2. Siegler, 1520.
3. Huba N, Zhang Y. Designing patient-centered personal health records (PHRs): health care professionals' perspective on patient-generated data. *J Med Syst*. 2012 May 30 [epub ahead of print].
4. Wibe T, Helleso R, Slaughter L, Ekstedt M. Lay people's experiences with reading their medical record. *Soc Sci Med*. 2011;72(9):1570-1573.
5. Castro CM, et al. Babel babble: physicians' use of unclarified medical jargon with patients. *Am J Health Behav*. 2007;31 Suppl 1:S85-S95.
6. Liaw T, Lawrence M, Rendell J. The effect of a computer-generated patient-held medical record summary and/or a written personal health record on patients' attitudes, knowledge and behaviour concerning health promotion. *Fam Pract*. 1996;13(3):289-293.

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STATE OF THE ART AND SCIENCE

Electronic Health Records: Privacy, Confidentiality, and Security

Laurinda B. Harman, PhD, RHIA, Cathy A. Flite, MEd, RHIA, and Kesa Bond, MS, MA, RHIA, PMP

Health Information Systems: Past and Present

To understand the complexities of the emerging electronic health record system, it is helpful to know what the health information system has been, is now, and needs to become. The medical record, either paper-based or electronic, is a communication tool that supports clinical decision making, coordination of services, evaluation of the quality and efficacy of care, research, legal protection, education, and accreditation and regulatory processes. It is the business record of the health care system, documented in the normal course of its activities. The documentation must be authenticated and, if it is handwritten, the entries must be legible.

In the past, the medical record was a paper repository of information that was reviewed or used for clinical, research, administrative, and financial purposes. It was severely limited in terms of accessibility, available to only one user at a time. The paper-based record was updated manually, resulting in delays for record completion that lasted anywhere from 1 to 6 months or more. Most medical record departments were housed in institutions' basements because the weight of the paper precluded other locations. The physician was in control of the care and documentation processes and authorized the release of information. Patients rarely viewed their medical records.

A second limitation of the paper-based medical record was the lack of security. Access was controlled by doors, locks, identification cards, and tedious sign-out procedures for authorized users. Unauthorized access to patient information triggered no alerts, nor was it known what information had been viewed.

Today, the primary purpose of the documentation remains the same—support of patient care. Clinical documentation is often scanned into an electronic system immediately and is typically completed by the time the patient is discharged. Record completion times must meet accrediting and regulatory requirements. The electronic health record is interactive, and there are many stakeholders, reviewers, and users of the documentation. Because the government is increasingly involved with funding health care, agencies actively review documentation of care.

The electronic health record (EHR) can be viewed by many users simultaneously and utilizes a host of information technology tools. Patients routinely review their electronic medical records and are keeping personal health records (PHR), which

contain clinical documentation about their diagnoses (from the physician or health care websites).

The physician, practice, or organization is the owner of the physical medical record because it is its business record and property, and the patient owns the information in the record [1]. Although the record belongs to the facility or doctor, it is truly the patient's information; the Office of the National Coordinator for Health Information Technology refers to the health record as "not just a collection of data that you are guarding—it's a life" [2]. There are three major ethical priorities for electronic health records: privacy and confidentiality, security, and data integrity and availability.

Privacy and Confidentiality

Justices Warren and Brandeis define privacy as the right "to be let alone" [3]. According to Richard Rognehaugh, it is "the right of individuals to keep information about themselves from being disclosed to others; the claim of individuals to be let alone, from surveillance or interference from other individuals, organizations or the government" [4]. The information that is shared as a result of a clinical relationship is considered *confidential* and must be protected [5]. The information can take various forms (including identification data, diagnoses, treatment and progress notes, and laboratory results) and can be stored in multiple media (e.g., paper, video, electronic files). Information from which the identity of the patient cannot be ascertained—for example, the number of patients with prostate cancer in a given hospital—is not in this category [6].

Patient information should be released to others only with the patient's permission or as allowed by law. This is not, however, to say that physicians cannot gain access to patient information. Information can be released for treatment, payment, or administrative purposes without a patient's authorization. The patient, too, has federal, state, and legal rights to view, obtain a copy of, and amend information in his or her health record.

The key to preserving confidentiality is making sure that only authorized individuals have access to information. The process of controlling access—limiting who can see what—begins with authorizing users. In a physician practice, for example, the practice administrator identifies the users, determines what level of information is needed and assigns usernames and passwords. Basic standards for passwords include requiring that they be changed at set intervals, setting a minimum number of characters, and prohibiting the reuse of passwords. Many organizations and physician practices take a two-tier approach to authentication, adding a biometrics identifier scan, such as palm, finger, retina, or face recognition.

The user's access is based on preestablished role-based privileges. In a physician practice, the nurse and the receptionist, for example, have very different tasks and responsibilities; therefore, they do not have access to the same information. Hence, designating user privileges is a critical aspect of medical record security: all users have access to the information they need to fulfill their roles and responsibilities, and

they must know that they are accountable for use or misuse of the information they view and change [7].

Under the HIPAA Privacy and Security Rules, employers are held accountable for the actions of their employees. In 2011, employees of the UCLA health system were found to have had access to celebrities' records without proper authorization [8]. UCLA failed to "implement security measures sufficient to reduce the risks of impermissible access to electronic protected health information by unauthorized users to a reasonable and appropriate level" [9]. The health system agreed to settle privacy and security violations with the U.S. Department of Health and Human Services Office for Civil Rights (OCR) for $865,000 [10]. Controlling access to health information is essential but not sufficient for protecting confidentiality; additional security measures such as extensive training and strong privacy and security policies and procedures are essential to securing patient information.

Security

The National Institute of Standards and Technology (NIST), the federal agency responsible for developing information security guidelines, defines *information security* as the preservation of data confidentiality, integrity, availability (commonly referred to as the "CIA" triad) [11]. Not only does the NIST provide guidance on securing data, but federal legislations such as the Health Insurance Portability and Accountability Act (HIPAA) and the Health Information Technology for Economic and Clinical Health (HITECH) Act mandate doing so. Violating these regulations has serious consequences, including criminal and civil penalties for clinicians and organizations.

The increasing concern over the security of health information stems from the rise of EHRs, increased use of mobile devices such as the smartphone, medical identity theft, and the widely anticipated exchange of data between and among organizations, clinicians, federal agencies, and patients. If patients' trust is undermined, they may not be forthright with the physician. For the patient to trust the clinician, records in the office must be protected. Medical staff must be aware of the security measures needed to protect their patient data and the data within their practices.

A recent survey found that 73 percent of physicians text other physicians about work [12]. How to keep the information in these exchanges secure is a major concern. There is no way to control what information is being transmitted, the level of detail, whether communications are being intercepted by others, what images are being shared, or whether the mobile device is encrypted or secure. Mobile devices are largely designed for individual use and were not intended for centralized management by an information technology (IT) department [13]. Computer workstations are rarely lost, but mobile devices can easily be misplaced, damaged, or stolen. Encrypting mobile devices that are used to transmit confidential information is of the utmost importance.

Another potential threat is that data can be hacked, manipulated, or destroyed by internal or external users, so security measures and ongoing educational programs must include all users. Some security measures that protect data integrity include firewalls, antivirus software, and intrusion detection software. Regardless of the type of measure used, a full security program must be in place to maintain the integrity of the data, and a system of audit trails must be operational.

Providers and organizations must formally designate a security officer to work with a team of health information technology experts who can inventory the system's users, and technologies; identify the security weaknesses and threats; assign a risk or likelihood of security concerns in the organization; and address them. The responsibilities for privacy and security can be assigned to a member of the physician office staff or be outsourced.

Audit trails. With the advent of audit trail programs, organizations can precisely monitor who has had access to patient information.

Audit trails track all system activity, generating date and time stamps for entries; detailed listings of what was viewed, for how long, and by whom; and logs of all modifications to electronic health records [14]. Administrators can even detail what reports were printed, the number of screen shots taken, or the exact location and computer used to submit a request. Alerts are often set to flag suspicious or unusual activity, such as reviewing information on a patient one is not treating or attempting to access information one is not authorized to view, and administrators have the ability to pull reports on specific users or user groups to review and chronicle their activity. Software companies are developing programs that automate this process. End users should be mindful that, unlike paper record activity, all EHR activity can be traced based on the login credentials. Audit trails do not prevent unintentional access or disclosure of information but can be used as a deterrent to ward off would-be violators.

The HIPAA Security Rule requires organizations to conduct audit trails [12], requiring that they document information systems activity [15] and have the hardware, software, and procedures to record and examine activity in systems that contain protected health information [16]. In addition, the HITECH Act of 2009 requires health care organizations to watch for breaches of personal health information from both internal and external sources. As part of the meaningful use requirements for EHRs, an organization must be able to track record actions and generate an audit trail in order to qualify for incentive payments from Medicare and Medicaid. HIPAA requires that audit logs be maintained for a minimum of 6 years [13]. As with all regulations, organizations should refer to federal and state laws, which may supersede the 6-year minimum.

Integrity and Availability

In addition to the importance of privacy, confidentiality, and security, the EHR system must address the integrity and availability of information.

Integrity. Integrity assures that the data is accurate and has not been changed. This is a broad term for an important concept in the electronic environment because data exchange between systems is becoming common in the health care industry. Data may be collected and used in many systems throughout an organization and across the continuum of care in ambulatory practices, hospitals, rehabilitation centers, and so forth. This data can be manipulated intentionally or unintentionally as it moves between and among systems.

Poor data integrity can also result from documentation errors, or poor documentation integrity. A simple example of poor documentation integrity occurs when a pulse of 74 is unintentionally recorded as 47. Whereas there is virtually no way to identify this error in a manual system, the electronic health record has tools in place to alert the clinician that an abnormal result was entered.

Features of the electronic health record can allow data integrity to be compromised. Take, for example, the ability to copy and paste, or "clone," content easily from one progress note to another. This practice saves time but is unacceptable because it increases risk for patients and liability for clinicians and organizations [14, 17]. Another potentially problematic feature is the drop-down menu. Drop-down menus may limit choices (e.g., of diagnosis) so that the clinician cannot accurately record what has been identified, and the need to choose quickly may lead to errors. Clinicians and vendors have been working to resolve software problems such as screen design and drop-down menus to make EHRs both user-friendly and accurate [17].

Availability. If the system is hacked or becomes overloaded with requests, the information may become unusable. To ensure availability, electronic health record systems often have redundant components, known as fault-tolerance systems, so if one component fails or is experiencing problems the system will switch to a backup component.

The Future

Some who are reading this article will lead work on clinical teams that provide direct patient care. Some will earn board certification in clinical informatics. Others will be key leaders in building the health information exchanges across the country, working with governmental agencies, and creating the needed software. Regardless of one's role, everyone will need the assistance of the computer.

Medical practice is increasingly information-intensive. The combination of physicians' expertise, data, and decision support tools will improve the quality of care. Physicians will be evaluated on both clinical and technological competence. Information technology can support the physician decision-making process with clinical decision support tools that rely on internal and external data and information. It will be essential for physicians and the entire clinical team to be able to trust the data for patient care and decision making. Creating useful electronic health record systems will require the expertise of physicians and other clinicians, information

management and technology professionals, ethicists, administrative personnel, and patients.

References

1. Odom-Wesley B, Brown D, Meyers CL. *Documentation for Medical Records*. Chicago: American Health Information Management Association; 2009:21.
2. Office of the National Coordinator for Health Information Technology. *Guide to Privacy and Security of Health Information*; 2012:5. http://www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf. Accessed August 10, 2012.
3. Warren SD, Brandeis LD. The right to privacy. *Harvard Law Rev*. 1890;4:193.
4. Rognehaugh R. *The Health Information Technology Dictionary*. Gaithersburg, MD: Aspen; 1999:125.
5. Rinehart-Thompson LA, Harman LB. Privacy and confidentiality. In: Harman LB, ed. *Ethical Challenges in the Management of Health Information*. 2nd ed. Sudbury, MA: Jones and Bartlett; 2006:53.
6. Rinehart-Thompson, Harman, 54.
7. American Health Information Management Association. The 10 security domains (updated). *J Am Health Inf Management Assoc*. 2012;83(5):50.
8. University of California settles HIPAA privacy and security case involving UCLA Health System facilities [news release]. Washington, DC: US Department of Health and Human Services; July 7, 2011. http://www.hhs.gov/news/press/2011pres/07/20110707a.html. Accessed August 10, 2012.
9. US Department of Health and Human Services Office for Civil Rights. UCLA Health System settles potential HIPAA privacy and security violations. http://www.hhs.gov/ocr/privacy/hipaa/news/uclahs.html. Accessed August 10, 2012.
10. US Department of Health and Human Services Office for Civil Rights. Resolution agreement [UCLA Health System]. http://www.hhs.gov/ocr/privacy/hipaa/enforcement/examples/UCLAHSracap.pdf. Accessed August 10, 2012.
11. National Institute of Standards and Technology Computer Security Division. *An Introduction to Computer Security: The NIST Handbook*. U.S. Department of Commerce. Gaithersburg, MD: NIST; 1995:5. http://csrc.nist.gov/publications/nistpubs/800-12/800-12-html/index.html. Accessed August 10, 2012.
12. Greene AH. HHS steps up HIPAA audits: now is the time to review security policies and procedures. *J Am Health Inf Management Assoc*. 2011;82(10):58-59. http://www.ahimajournal-digital.com/ahimajournal/201110?pg=61#pg61. Accessed August 10, 2012.
13. American Health Information Management Association. Mobile device security (updated). *J Am Health Inf Management Assoc*. 2012;83(4):50.

http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_049463.hcsp?dDocName=bok1_049463. Accessed August 10, 2012.
14. American Health Information Management Association. Copy functionality toolkit; 2008:4. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_042564.pdf#xml=http://library.ahima.org/xpedio/idcplg?IdcService=GET_XML_HIGHLIGHT_INFO&QueryText=%28cut+copy+and+paste%29%3Cand%3E%28xPublishSite%3Csubstring%3E%60BoK%60%29&SortField=xPubDate&SortOrder=Desc&dDocName=bok1_042564&HighlightType=PdfHighlight. Accessed August 10, 2012.
15. US Department of Health and Human Services. Security standards: general rules, 46 CFR section 164.308(a)-(c).
16. US Department of Health and Human Services. Technical safeguards. 45 CFR section 164.312(1)(b).
17. American Health Information Management Association. Auditing copy and paste. *J Am Health Inf Management Assoc*. 2009;80(1):26-29. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_042416.hcsp?dDocName=bok1_042416. Accessed August 10, 2012.

Further Reading

American Health Information Management Association web site. http://www.ahima.org. Accessed August 10, 2012.

American Health Lawyers Association. *Red Flag Compliance for Health Care Providers: Protecting Ourselves and our Patients from Identity Theft Member Briefing*. Chicago: American Health Information Management Association; 2010.

American Medical Informatics Association web site. http://www.amia.org. Accessed August 10, 2012.

Amatayakul MK. *Electronic Health Records: A Practical Guide for Professionals and Organizations*. 5th ed. Chicago: American Health Information Management Association; 2012.

Amatayakul MK, Lazarus S. *Electronic Health Records: Transforming Your Medical Practic*e. Englewood, CO: Medical Group Management Association; 2010.

Baldwin KA, Ball K, Dougherty M, Hedges RJ. *e-Discovery and Electronic Records*. Chicago: American Health Information Management Association; 2012.

Dennis JC. *Privacy: The Impact of ARRA, HITECH, and Other Policy Initiatives*. Chicago: American Health Information Management Association; 2011.

LaTour KM, Eichenwald Maki S, eds. *Health Information Management: Concepts, Principles, and Practice*. 3rd ed. Chicago: American Health Information Management Association; 2010.

MGMA-AHIMA Smart Pack. *Health Information Technology: Implementing an Electronic Health Record in Physician Practices.* Chicago: American Health Information Management Association; 2006.

Trites PA, Gelzer RD. *How to Evaluate Electronic Health Records*. Chicago: American Health Information Management Association; 2008.

Wolter J. *The Personal Health Record*. Chicago: American Health Information Management Association; 2009.

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HEALTH LAW

Patient-Physician Confidentiality: 'Til Death Do Us Part?

Courtney Mathews and Andreia Martins Martinho

A substantial amount of legal and ethical attention focuses on physicians' duty to maintain the confidentiality of personal medical information. The necessary role of trust in fiduciary relationships, the personal and social consequences of medical practice, and the intrinsic value of medical privacy all justify upholding a patient's interests in confidentiality [1]. Society, on the other hand, has a legitimate interest in permitting, and sometimes legally requiring, breaches of confidentiality. One major point of contention is whether there are justifiable reasons to disclose a patient's medical information postmortem. Confidential medical information may be sought after a patient's death in a variety of scenarios, including family members' seeking information pertaining to their own health, researchers' investigating public health concerns, and information sought for the public's knowledge [1]. Each situation poses particular challenges for health care professionals who must decide whether or not to disclose a deceased patient's medical information.

The federal Health Insurance Portability and Accountability Act's (HIPAA) Privacy Rule governs many areas of patient confidentiality, including postmortem cases. HIPAA requires health services providers to ensure the confidentiality and availability of health information that could identify an individual. Specifically for the release of postmortem health information, HIPAA has been interpreted to allow family members access to the protected health information of deceased relatives in two ways: (1) disclosure of relevant health information to a physician who is treating a surviving relative and (2) access by a legally authorized representative, like the holder of a health care power of attorney for the deceased [2]. While this general guidance is useful for physicians, HIPAA does not speak specifically or in great detail to the particular circumstances in which physicians most often see requests for postmortem release of medical information. In these scenarios discussed below, additional considerations and guidance may apply.

Genetic Diagnoses

Genetic information creates significant challenges to postmortem confidentiality, because genetic diagnoses may have health implications for the decedent's blood relatives. In *Safer v. Estate of Pack*, a woman sued her deceased father's physician for failing to warn her that her father's death had been caused by a potentially heritable form of colon cancer [3]. She did not know about her father's polyposis diagnosis, which occurred when she was a child, until she too was diagnosed with multiple polyposis and cancer at age 36. She argued that the physician knew about the hereditary nature of the disease and had a duty to warn those at risk. The New

Jersey court agreed that physicians' "duty to warn might not be satisfied in all cases by informing the patient," and that, in those cases, the physician might have to balance the duty to warn at-risk relatives with fidelity to patient confidentiality [3]. Thus, at least one state judicially protects physicians who disclose genetic information to at-risk family members who can benefit from the disclosure.

Legislatively, some states have enacted laws completely upholding the confidentiality of genetic information, and other states require that confidentiality be maintained with exceptions [4]. For example, Oregon permits disclosure of genetic information when it is pertinent to medical diagnosis of blood relatives of the decedent [5].

Research Results

To legally disclose research findings of participants who have died, HIPAA requires researchers to obtain permission from a representative of the deceased [6]. Even disclosure of deidentified information is prohibited by HIPAA except when there is cause to believe that the information cannot be used to identify the research participant [7].

While it may seem that disclosing genome-related research results postmortem would be unwelcome and upsetting to family members, one small study found the opposite [8]. The study of 13 relatives of a deceased clinical study participant revealed that they did not think that the genetic samples collected from their deceased relative should be irreversibly anonymized. Moreover, all "believed that genetics research results of clinical significance should be fed back to relatives" [9].

Autopsy Reports

Lastly, medical information about a deceased patient may be sought for general interest, especially if the individual in question is a public figure. After Dale Earnhardt's death in a race car crash, *The Orlando Sentinel*'s request to access autopsy photographs ignited controversy about whether autopsy photographs could be released to the public over familial pleas for privacy [10]. *The Sentinel* wanted the photographs to determine whether certain safety measures might have saved Earnhardt's life, but his widow, Teresa Earnhardt, sought an injunction to block the release of any autopsy photograph [10]. Earnhardt's family and *The Sentinel* reached a legal settlement that provided for the inspection, but not copying, of the photographs by an independent expert in biomechanics [10].

Access to autopsy reports is largely governed by state laws, because most autopsies are performed by state coroners. Before the Dale Earnhardt controversy, Florida, like many states, did not have well-defined law on the topic but was known as an "extremely access-friendly state" [11]. Now, Florida law requires that anyone seeking to view or copy a photograph, videotape, or audio recording of an autopsy must show good cause in court and provide the surviving spouse or family with notice of any hearing [12]. While some states have been influenced by Florida and have passed legislation to ban or limit access to autopsy records, other states have

resisted such efforts. For example, in 2005, under pressure from newspaper publishers, the Wyoming legislature voted against a bill that would have denied the public access to autopsy records [11].

Guidance for Physicians

The American Medical Association adopted guidelines to help physicians resolve conflicts between a patient's right to privacy and a third party's right to know. Opinion 5.051 of the AMA's *Code of Medical Ethics* states that, in deciding whether disclosure of medical information postmortem is appropriate, the following factors must be considered: (1) the imminence of harm to identifiable individuals or the public health; (2) the potential benefit to at-risk individuals or the public health; (3) any statement or directive made by the patient regarding postmortem disclosure; (4) the impact disclosure may have on the reputation of the deceased patient; and (5) personal gain for the physician that may unduly influence him or her [13].

Further, the AMA suggests that protection of the confidentiality of medical information postmortem be equal to the protections in effect during a patient's life. Medical information during life is granted a significant amount of protection, subject only to legal requirements to disclose and overriding considerations that ethically justify disclosure (and then, only minimal information may be disclosed) [14]. Because maintaining strict confidentiality is often untenable, or even illegal, determining the extent of protections in the postmortem context ultimately entails a weighing of the various interests at stake.

References

1. Berg J. Grave secrets: legal and ethical analysis of postmortem confidentiality. *Conn Law Rev*. 2001;34:81-122.
2. US Department of Health and Human Services Office for Civil Rights. Health information privacy: frequently asked questions: how can family members of a deceased individual obtain the deceased individual's protected health information that is relevant to their own health care? http://www.hhs.gov/ocr/privacy/hipaa/faq/right_to_access_medical_records/222.html. Accessed July 6, 2012.
3. *Safer v Estate of Pack*, 677 A2d 1188 (NJ Supp 1996).
4. King M. Physician duty to warn a patient's offspring of hereditary genetic defects: balancing the patient's right to confidentiality against the family member's right to know—can or should Tarasoff apply? *Quinnipiac Health Law J*. 2000;4(1):1-38.
5. Disclosure of genetic information; exceptions. Or Rev Stat section 192.539 (2011).
6. Health Information Portability and Accountability Act of 1996, 45 CFR 164.502(g)(4) (2012).
7. Tasse A. Return of research results: how should research results be handled?: the return of results of deceased research participants. *J Law Med Ethics*. 2011;39(4):621-630.

8. Ormondroyd E, Moynihan C, Watson M, et al. Disclosure of genetics research results after the death of the patient participant: a qualitative study of the impact on relatives. *J Genetic Couns*. 2007; 16(4): 527-538.
9. Ormondroyd, et al, 527.
10. Terilli S, Splichal SL. Public access to autopsy and death-scene photographs: relational privacy, public records, and avoidable collisions. *Comm Law Policy*. 2005;10(3):313-348.
11. Cameron C. Not getting to yes: why the media should avoid negotiating access rights. *Thomas Cooley Law Rev*. 2007;24(2):237-262.
12. Autopsies; confidentiality of photographs and video and audio recordings; exemption, Fla Stat section 406.135(4)(a)-(c).
13. American Medical Association. Opinion 5.051 - Confidentiality of medical information postmortem. *Code of Medical Ethics*. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion5051.page. Accessed August 14, 2012.
14. American Medical Association. Opinion 5.05 - Confidentiality. *Code of Medical Ethics*. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion505.page. Accessed August 14, 2012.

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POLICY FORUM

Would Patient Ownership of Health Data Improve Confidentiality?

Barbara J. Evans, PhD, JD, LLM

Introduction

Modern testing technology can extract a wealth of information from the merest speck of a person—a biospecimen—and information systems can transmit entire medical records at the click of a mouse. Given these capabilities, confidentiality—the notion that information patients share during medical treatment should not be disclosed to others without the patient's authorization—is a fragile concept [1]. One response to patient concerns about confidentiality has been to press state legislators to give patients actual ownership of their medical information. Five states have done so with respect to genetic information [2], and a number of other states are considering whether to recognize patient ownership of health records [3].

It seems obvious, at first glance, that "[h]ow the law defines ownership of patient data…affects patient confidentiality" [4]. However, letting patients own their health records may not be an effective way to improve confidentiality. Although it seems counterintuitive, the protections patients currently enjoy under the Health Insurance Portability and Accountability Act (HIPAA) [5] Privacy Rule [6] and the Common Rule [7] are surprisingly similar to those they would have if they owned their data and biospecimens [8].

The Framework of Protections under HIPAA and the Common Rule

The HIPAA Privacy Rule and the Common Rule require, as their baseline, that patients sign privacy authorizations [9] or informed consent forms [10] (or both) before another party can gain access to their medical information or biospecimens. Access to data and specimens is consensual in the sense of requiring the patients' permission. Both regulations, however, shift to a regime of nonconsensual access—that is, access without authorization or informed consent--in various situations [11-15]. The Department of Health and Human Services (HHS) recently published an advance notice of proposed rulemaking (ANPRM) [16] that explored possible changes to the Common Rule. The proposal, if implemented, would alter some of the details regarding when consent is required but would continue to allow nonconsensual access under certain circumstances [17-20].

The HIPAA Privacy Rule and the Common Rule currently allow nonconsensual access to data and tissues for certain uses believed to have a high social value—for example, public health, judicial, and law enforcement activities. Nonconsensual *research* uses of data and biospecimens are allowed under various conditions that purport to manage the risks to patient confidentiality by, for example, de-identifying

or coding data in compliance with specific standards [15, 21-25] or converting the data to a limited data set as defined in the HIPAA Privacy Rule [26]. An additional way to gain access to data and biospecimens for research is to have an institutional review board or privacy board (collectively, IRB) [27-30] approve a waiver of the baseline consent or authorization requirements [31, 32].

When data are supplied to researchers under a HIPAA waiver, there is a "minimum necessary" [33] requirement, meaning that no more information can be disclosed than is required to accomplish the goals of the research. However, HIPAA does not require the data or biospecimens to be de-identified or even coded when granting a waiver. In theory, identified data or specimens could be disclosed to researchers under a waiver if the identifiers are necessary to the research and if an IRB determines that several other waiver conditions have been met [34].

Obviously, the HIPAA Privacy Rule and the Common Rule do not ensure "confidentiality" in the ordinary sense of the word. Both regulations allow information shared during medical consultation (and specimens collected during treatment) to be disclosed to third parties without the patient's permission. The protections these regulations provide do not live up to many people's notion of "confidentiality." This situation explains the recent push for patient ownership of medical information and biospecimens.

If Patients Owned Their Data

Would a regime of patient data ownership do a better job of protecting confidentiality? In popular conception, ownership confers a solid, indisputable right of control. Unfortunately, this is not how property rights actually work.

Consider, by way of comparison, ownership of a home (assuming it is paid in full and free of any mortgage). In the ordinary course of things, a person wishing to use your home must enter a consensual transaction with you, and you are free to define the terms of that transaction, such as the price at which you would be willing to sell or lease the property. If someone uses your home without your consent, the law affords you an injunction remedy—courts and law enforcement authorities will help you stop the unwanted use [35]. This package of rights and remedies is what lawyers refer to as "property-rule" protection [36]. People who call for patient ownership of data often seem to have this type of protection in mind: all uses of data would require the patient's consent on terms defined by the patient, and unconsented uses could be enjoined (forced to stop).

Owning a home does not, unfortunately, ensure this sort of protection. There are many situations where consensual ordering breaks down. If a neighbor's Fourth-of-July fireworks burn down your house, there is no opportunity beforehand to negotiate a consensual transaction in which you agree to a price at which you would be willing to have your house destroyed. The deed is done; the house has been taken nonconsensually, and it is too late to enjoin the violation of your rights. Instead, law grants you what is known as "liability-rule" protection: you may petition a court to

set an appropriate level of compensation for your loss [37]. Tort lawsuits are the most famous example of liability-rule protection, but there are many others, including two that have particular salience in the context of data ownership: (1) actions the state takes under its police power to protect the public's health, safety, morals, or welfare [38], and (2) eminent domain.

The state's police power to use patient-owned data. If a home is poorly maintained and poses a threat to neighboring properties, the state can order it cleaned up or demolished without the owner's consent. In these situations, the government usually does not owe the homeowner compensation for the loss. In the nineteenth century, courts analyzed such cases under natural rights principles that grounded property rights in personhood [39]. These old cases are intriguing because their reasoning bears a surprising resemblance to modern bioethical analysis that grounds privacy rights in autonomy. The natural-rights rationale for allowing the state to place burdens on the property owner was that a person has no natural right to harm his neighbors and thus suffers no compensable loss of rights when the state steps in to protect their interests [40].

Even when a home is well maintained and poses no risk to others, the state still can interfere with property rights in ways that promote public health and welfare—for example, by passing laws that force owners to install sidewalks at their own expense. The natural-rights rationale for forcing owners to bear these costs was that each affected owner receives "implicit in-kind" [41] compensation: there is "reciprocity of advantage" [42, 43] since each affected owner benefits from the improvements fellow citizens are similarly forced to make [41, 44]. The scope of the state's police power thus includes a power to force owners to contribute positive benefits to the community; it is not limited to controlling nuisances and harms [45]. However, nineteenth-century courts set limits on the state's power to force people to make positive contributions for the good of the public. The state could validly ask people to do so only when there was reciprocity of advantage, so that each person who gave to the community also got something back from it.

Public health activities long have been viewed as legitimate exercises of the state's police power [46, 47]. The reciprocity-of-advantage concept in nineteenth-century property law resonates with a concept used in modern bioethical analysis of public health uses under the Common Rule. When deciding whether a proposed study is public health "practice" or public health "research" [48-50], some IRBs inquire whether the study will offer "benefits internal to the community" [51, 52]. When benefits of a study flow to the people who contributed data or specimens, this tends to favor a finding that the study is public health practice that does not require consent under the Common Rule. If the study benefits groups other than the data or specimen contributors, this tends to support a finding that the use is research that does require consent.

This resonance between nineteenth-century natural-rights analysis and contemporary bioethical thought is no accident. When the benefits of a study are internal to the

community, this is merely another way of saying that there is reciprocity of advantage. Modern bioethical analysis of public health uses under the Common Rule is strikingly similar to the natural-rights analysis nineteenth-century courts applied when analyzing police-power intrusions on individual property rights. Bioethicists might draw upon these cases for insights on how to make difficult ethical trade-offs when there is conflict between individual autonomy and public interests.

Even if patients owned their data and biospecimens, these resources still could be used in public health activities without their permission—the same level of protection that patients already have under the HIPAA Privacy Rule and the Common Rule. Both regulations allow nonconsensual access to data and biospecimens to benefit public health.

Eminent domain and patient-owned data. The state has an additional power known as eminent domain or "takings" power. The significance of this power in the present discussion is that the state can pass laws that take a person's property without consent, even when there is no reciprocity of advantage—that is, when the burdens of a measure to benefit the public are disproportionately visited on a few members of the community [53].

The state can take a person's home to build a new sports stadium, even when the owner is not a sports fan and will never personally enjoy the new facility. Even if the affected homeowner theoretically shares in the benefits of a project—as with a highway project—the benefits and burdens may be so badly skewed that there is no way to pretend the owner will receive in-kind compensation for the loss. The joys of driving on a new highway are a shabby reward for losing one's home. The Supreme Court considers it a "taking" when governmental action forces "some people alone to bear public burdens which, in all fairness and justice, should be borne by the public as a whole" [54]. The government still can force the owner to give up her property, but the owner is entitled to receive "just compensation" under the Fifth Amendment to the U.S. Constitution.

In a longer study [55], summarized below, I explored the analogy between eminent domain doctrine and unconsented uses of data and biospecimens in research. "Research," as defined in the HIPAA Privacy Rule and the Common Rule [56, 57], produces findings that are generalizable to populations other than the participants whose data are being used. Nonconsensual uses of data in research cannot be justified under a reciprocity-of-advantage rationale because, quite often, the data and specimen contributors derive no benefits whatsoever. If patients owned their data and biospecimens, eminent domain seemingly would be the only available legal mechanism for procuring these resources for use in research without patient consent. The question is, "How would that work?" The major conclusions are as follows:

1. Under current legal precedents concerning property rights, it would be possible to take data and specimens for use in private, commercial research projects that offer the prospect of developing a beneficial new therapy [58].

Such takings could be allowed even when the new therapy would only be available to patients who could afford to pay for it. In other words, patient-owned data could be taken without consent for use in research sponsored by pharmaceutical and medical device companies.

2. It is unlikely that patients would receive monetary compensation when their data and tissues were taken for use in research [59]. Courts interpret "just compensation" to mean fair market value for property. Courts give no compensation for above-market subjective value an owner may place on a property—if, for example, the owner grew up in the house or her children decorated its walls with hand-painted frescoes that she treasures but that other buyers would not value similarly [60]. There also is no compensation for undeveloped use rights [61, 62]—the value an unused piece of land might have had if the owner had chosen to build a palace on it. These same limitations presumably would restrict compensation for data and biospecimens.

   When patients want their data to remain unused because of privacy or dignitary concerns, the fair market value of the data apparently would be zero: there is no alternative, consensual data use by which to assess the data's fair market value. The value (in the patient's mind) of keeping data unused would most likely be viewed as a subjective value or an undeveloped use right, for which the patient would receive no compensation under modern takings doctrine.

3. There is a long tradition in the United States of laws that allow private bodies to approve takings of property. For example, railroad companies have been allowed to approve takings of property to assemble railroad rights-of-way for tracks. This so-called "private" eminent domain power is surprisingly similar to the role IRBs play under the waiver provisions of the HIPAA Privacy Rule and the Common Rule. The waiver provisions are consistent with American legal traditions that date back to the colonial era. If patients owned their data, some scheme of private eminent domain power would probably emerge, and it very well might resemble the waiver provisions that exist in current regulations [63]. Here, it is interesting to note that two of the five states that have recognized patients' ownership in genetic information have implemented schemes that allow unconsented use of this information in research [64].

Conclusion

There are few discernible differences between the level of confidentiality patients would enjoy if they owned their data and biospecimens and what they presently have under the HIPAA Privacy Rule and the Common Rule. A property regime would, however, impose a takings criterion known as a "public use" requirement that would help ensure that eminent domain takings of data and tissues must serve a socially beneficial purpose [65].The HIPAA Privacy Rule and the Common Rule currently

lack such a criterion in their waiver provisions, leaving patients with no assurance that unconsented uses of their data and specimens would serve a useful purpose. This is a point on which the HIPAA Privacy Rule and the Common Rule need reform [65]. Many bioethicists agree that the "central ethical issue" [66] in unconsented use of data or biospecimens is whether the public benefits to be gained from the use are great enough to justify the burden it will place on the data or tissue contributors [67]. The current waiver provisions do not adequately address this question.

Patients' concern about confidentiality, however, does not really turn on how their data and specimens are used. Confidentiality, in many patients' minds, is breached by *any* unauthorized use of a patient's data or biospecimens, regardless of the benefits to be gained by the use. From the standpoint of protecting patients' confidentiality, data ownership offers little improvement over the HIPAA Privacy Rule and the Common Rule. This suggests that patient ownership of data is not a fruitful path for reform. It would leave patients with many of the same dissatisfactions they have with the current regulations.

References

1. Nass SJ, Levit LA, Gostin LO eds.; Institute of Medicine Committee on Health Research and the Privacy of Health Info. *Beyond The HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research.* Washington, DC: National Academies Press; 2009. http://www.nap.edu/catalog/12458.html. Accessed August 8, 2012.
2. The five states are Alaska, Colorado, Florida, Georgia, and Louisiana. Ram N. Assigning rights and protecting interests: constructing ethical and efficient rights in human tissue research. *Harvard J Law Tech*. 2009;23(1):141.
3. Evans BJ. Much ado about data ownership. *Harvard J Law Tech*. 2012;25(1):69-130.
4. Rodwin MA. Patient data: property, privacy & the public interest. *Am J Law Med*. 2010;36(4):586-618.
5. Health Insurance Portability and Accountability Act of 1996, Pub L No 104-191, 110 Stat 1936 (codified as amended in scattered sections of 18, 26, 29 and 42 USC).
6. US Department of Health and Human Services (HHS). Standards for Privacy of Individually Identifiable Health Information (HIPAA Privacy Rule), codified at 45 CFR parts 160, 164.
7. HHS. Basic HHS Policy for Protection of Human Subjects (Common Rule), 45 CFR part 46 subpart A (sections 46.101-46.124).
8. Evans (2012), 77-86.
9. HHS. Uses and disclosures for which an authorization is required, 45 CFR section 164.508.
10. HHS. General requirements for informed consent, 45 CFR section 46.116.
11. HHS. Uses and disclosures for which an authorization or opportunity to agree or object is not required, 45 CFR section 164.512.
12. HHS. Human subject research to which the policy applies. Basic HHS Policy for Protection of Human Subjects, 45 CFR sections 46.101(b)–(d).

13. HHS. Definition of research. 45 CFR section 46.102(d).
14. HHS. Definition of human subject. 45 CFR section 46.102(f).
15. The US Department of Health and Human Services Office for Human Research Protections (OHRP) has determined that research involving only coded private information and biospecimens is not human subject research that requires informed consent. *See* Office for Human Research Protections. Guidance on research involving coded private information or biological specimens; Oct. 16, 2008. http://www.hhs.gov/ohrp/policy/cdebiol.html. Accessed July 15, 2012.
16. HHS. Advanced notice of proposed rulemaking: human subjects research protections: enhancing protections for research subjects and reducing burden, delay, and ambiguity for investigators. *Fed Regist*. 2011;76:44512-44531. To be codified at 45 CFR parts 46, 160, 164, and 21 CFR parts 50, 56. https://www.federalregister.gov/articles/2011/07/26/2011-18792/human-subjects-research-protections-enhancing-protections-for-research-subjects-and-reducing-burden. Accessed August 9, 2012.
17. HHS. *Fed Regist*. 2011;76:44518-44521.
18. HHS, *Fed Regist*. 2011;76:44527, table 1, Proposal for the excused category of research involving pre-existing information or biospecimens. https://www.federalregister.gov/articles/2011/07/26/2011-18792/human-subjects-research-protections-enhancing-protections-for-research-subjects-and-reducing-burden#t-1. Accessed August 9, 2012.
19. But the same document suggests that consent could be waived in certain circumstances. HHS. *Fed Regist*. 2011;76:44523-44525.
20. Public comment was sought on whether certain activities, such as quality-improvement and public-health activities, should lie outside the Common Rule's consent requirements. HHS. *Fed Regist*. 2011;76:44521 question 24.
21. Part of 45 CFR 164.514 allows data to be de-identified, for HIPAA purposes, by stripping away eighteen specific types of identifiers or by having a statistician certify that the risk of re-identification is "very small." *See* Other requirements relating to uses and disclosures of protected health information, 45 CFR section 164.514(b).
22. The definition of "human subject" in subpart A means that research with data is not covered by the Common Rule's consent requirements if investigators do not receive identifying information or interact with the subjects. *See* Basic HHS Policy for Protection of Human Research Subjects, 45 CFR section 46.102(f).
23. The advanced notice of proposed rulemaking, on the other hand, proposes a consent requirement for some uses of de-identified data that would not presently require consent under the Common Rule. HHS. *Fed Regist*. 2011;76:44519.
24. HHS. *Fed Regist*. 2011;76:44523.
25. Coded data is considered "de-identified" under the HIPAA Privacy Rule if the code key is derived in a certain way and if there are restrictions on access to the code key. *See* HHS. Other requirements relating to uses and disclosures of protected health information, 45 CFR section 164.514(c).

26. HHS. Other requirements relating to uses and disclosures of protected health information, 45 CFR section 164.514(e).
27. HHS. Assuring compliance with this policy -- research conducted or supported by any Federal Department or Agency, 45 CFR section 46.103(b).
28. HHS. IRB membership, 45 CFR 46.107.
29. HHS. IRB functions and operations, 45 CFR 46.108.
30. HIPAA waivers can be approved by either a Common Rule-compliant IRB or by a HIPAA-compliant "privacy panel" similar to an IRB. *See* HHS. Uses and disclosures for which an authorization or opportunity to agree or object is not required, 45 CFR section 164.512(i)(2)(iv).
31. HHS. Uses and disclosures for which an authorization or opportunity to agree or object is not required, 45 CFR section 164.512(i).
32. HHS. General requirements for informed consent. 45 CFR section 46.116(d).
33. HHS. Other requirements relating to uses and disclosures of protected health information, 45 CFR section 164.514(d).
34. Evans BJ. Ethical and privacy issues in pharmacogenomic research. In: Macleod HL, ed. *Pharmacogenomics: Applications to Patient Care*. 2nd ed. Lenexa, KS: American College of Clinical Pharmacy; 2009:313-338.
35. Merrill TW. The economics of public use. *Cornell Law Rev*. 1986;72:61-116.
36. Calabresi G, Melamed AD. Property rules, liability rules, and inalienability: one view of the cathedral. *Harvard Law Rev*. 1972;85(6):1089-1128.
37. Calabresi, Melamed, 1092.
38. Merrill, 66.
39. Claeys ER. Takings, regulations, and natural property rights. *Cornell Law Rev*. 2003;88(6):1549-1671.
40. Claeys, 1578.
41. Claeys, 1589.
42. Claeys ,1587-1589.
43. Claeys, 1619-1621.
44. Claeys, 1557.
45. Hart JF. Land use law in the early republic and the original meaning of the takings clause. *Northwestern Univ Law Rev*. 2000;94:1099-1156.
46. Hall MA. Property, privacy, and the pursuit of interconnected electronic medical records. *Iowa Law Rev*. 2010;95(2):631-663.
47. Parmet WE. After September 11: rethinking public health federalism. *J Law Med Ethics*. 2002;30(2):201-211.
48. Amoroso PJ, Middaugh JP. Research vs. public health practice: when does a study require IRB review? *Preventive Med*. 2003;36:250-253.
49. Centers for Disease Control and Prevention. HIPAA privacy rule and public health. *MMWR Morb Mortal Wkly Rep*. 2003;52:1-20. http://www.cdc.gov/mmwr/pdf/other/m2e411.pdf. Accessed July 15, 2012.
50. Snider DE Jr, Stroup DF. Defining research when it comes to public health. *Pub Health Rep*. 1997;112(1): 29-32.
51. Hodge JG, Gostin LO. Public health practice vs. research. Council of State and Territorial Epidemiologists; 2004:7.

http://www.cste.org/pdffiles/newpdffiles/CSTEPHResRptHodgeFinal.5.24.04.pdf. Accessed July 15, 2012.
52. Hodge JG. An enhanced approach to distinguishing public health practice and human subjects research. *J Law Med Ethics*. 2005;33(1):125-140.
53. Claeys, 1570.
54. *Armstrong v United States*, 364 US 40, 49 (1960).
55. Evans (2012), 80-86.
56. *See* HHS. Definitions. 45 CFR section 164.501.
57. *See* HHS. Human subject research to which the policy applies. 45 CFR section 46.101(d).
58. Evans (2012), 80-81.
59. Evans (2012), 81-82.
60. Bell A, Parchomovsky G. The hidden function of takings compensation. *Virginia Law Rev*. 2010;96:1673-1725.
61. Claeys, 1600-1601.
62. Claeys, 1632.
63. Evans (2012), 84-86.
64. Ram, 141 (listing Colorado and Georgia).
65. Evans (2012), 119-129.
66. Casarett D, Karlawish J, Andrews E, Caplan A. Bioethical issues in pharmacoepidemiologic research. In: Strom BL, ed. *Pharmacoepidemiology*. 4th ed. Chicester, UK: John Wiley & Sons; 2005: 597.
67. Jacobson PD. Medical records and HIPAA: is it too late to protect privacy? *Minn Law Rev*. 2002;86(6):1497-1514.

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MEDICINE AND SOCIETY

Confidentiality: Concealing "Things Shameful to be Spoken About"

Sue E. Estroff, PhD, and Rebecca L. Walker, PhD

A requirement to uphold the confidentiality of information shared in the physician-patient relationship is a central tenet of medical professionalism that, while at risk and undermined in various ways in modern medicine [1], has been consistently endorsed from the time of Hippocrates. This essay addresses confidentiality less in medical professionalism terms than in terms of the roots and impact of medical confidentiality in society more broadly. We investigate, in particular, the moral basis of confidentiality beyond a requirement of professionalism, contextual features of societies (institutions, roles, and cultures) that may affect confidentiality, and social expectations of—and challenges to—confidentiality.

In considering the moral basis of a requirement to uphold the confidentiality of information shared in the physician-patient relationship, it is first necessary to distinguish the related concepts of privacy and confidentiality. Privacy is about access to the person (her body, her choices, and certain kinds of information about her) while confidentiality is an expectation of control or limitation on disclosure of information shared by the patient with a privileged person. Privacy can be "invaded," while confidentiality is "breached" [2]. Thus, while a physician may, in some sense, invade the privacy of her patient by gaining personal health information or by physical exam, she does not breach confidentiality unless she—wittingly or unwittingly—shares the information gleaned with third parties not covered by their covenant.

Because the information physicians routinely elicit in the process of providing care is often of a very private nature, the willingness of patients to share this information and give physicians access to their bodies is based in part on their trust that the information will be held in confidence. Breaches of confidentiality, then, have the potential for doubly negative consequences—both harm to the patient (by making formerly private information public) and damage to her trust in the relationship (which is crucial for diagnosis and treatment of illness).

Breaches of confidentiality can occur, however, even when negative consequences do not (e.g., disclosures that do not harm a patient or of which a patient is unaware). If even these breaches of confidentiality are morally impermissible, what is that basis for that claim? One common presumption in the literature is that a requirement to uphold confidentiality is based in a moral requirement to respect patient autonomy [3-5], but respect for autonomy seems most relevant to protecting freedom of choice

rather than protection of private information or bodily access—the features of privacy most salient for medical confidentiality.

Consider, too, the critical role of protection of confidentiality in the Hippocratic Oath—a document that bears no mark of respect for patient autonomy. In that context, the physician must not reveal "such things [as are] shameful to be spoken about" [6], bringing to mind the significant social context of determining what is "shameful" to speak about (though not thereby shameful in itself) and invoking the dictum against such revelation seemingly independently of harmful effects to the patient. While we may, in a modern context, question what should or should not be "shameful" to reveal, we cannot escape the social and contextual rendering of some aspects of the self as private.

Generally speaking, the moral and social heft of confidentiality stems largely from the intimate personal nature of illness and its treatments, and from the trusting relationships on which health care is based. As quasisacred as these commitments may be in medicine, their commonsense meanings and importance derive from deeply held cultural understandings of sociality, individuality, citizenship, and bodily integrity, reflected in a variety of sacred and secular practices. In particular, expectations regarding what is private and why depend on cultural context. In an American context, we "respect the privacy" of grieving families by custom and consider genitalia to be "privates," yet other cultural practices call for grief to be enacted publicly and endorse different rules for which parts of the body are private, and should be covered when and with whom.

Recognizing an array of culturally informed habits and preferences about privacy and confidentiality in medicine is often subsumed under the banner of cultural competence. Caution is in order, however, because "among-those-people" formulas are shortcuts that may not reflect family or individual expectations and traditions. It would be risky to base a presumption of cultural differences in privacy practices on the language or dress of a patient's spouse or parents, for example. Generational variations in acculturation are always a possibility as well. Furthermore, familial expectations may not reflect the will or interest of the individual patient, for whom the physician is the fiduciary. The basic tenets of patient-centered doctoring require what Linda Hunt refers to as "humility" about difference [7]—that each patient's sensibilities be learned, not predicted or prescribed.

Focusing on cultural difference can easily distract attention from the ways in which social roles and contexts influence confidentiality practices. Differences in what information is shared, how, and with whom, between a rural private practice and an urban hospital setting, for example, are legion. In a "systems-based" hospital practice, the scope and complexity of care mean that the patient's medical needs are met by a small army, making intimacy-based trust difficult, if not preposterous [1]. In rural communities, on the other hand, patients may be concerned about the intimacies of a small town leading to unwitting exposure "because there is less anonymity and sometimes a faster flow of information" [8].

Sancar et al. reviewed the extant research on patient understandings of confidentiality and concluded that many patients are confused by, and misinformed about, confidentiality provisions and protections, often over- or underestimating protections of information they consider private [9]. At the same time, patients' values regarding confidentiality appear reasonable; they generally recognize physicians' need to share patient information with one another, but consistently uphold the conviction that access to medical information should be restricted to people involved in patient care [10].

The literature to date on patient perspectives on confidentiality has focused on (sometimes overlapping) groups that may be particularly in need of confidentiality: adolescents and seekers of genetic testing, HIV/AIDS testing, and mental health care [11]. Recognizing their social roles and social and personal expectations and assumptions regarding their medical care is important. Adolescents may be particularly concerned about sharing information with their parents or guardians, while others seeking sensitive care may be concerned about revelations to life and long-term care insurers and others who determine their future insurability or could discriminate against or exclude them. Some patients with psychiatric diagnoses or genetic or "lifestyle" risks such as smoking or drug use ask their physicians to keep such information "off the books," further complicating the questions of information control between patients and doctors.

Goffman identifies information control as a major concern for people who fear being stigmatized [12]. In his terminology, a person with a known or visible impairment is "discredited," while someone whose malady is not apparent fears disclosure and is "discreditable." In both circumstances, information control is paramount, and in our current health care system quandaries ensue about the "ownership" of medical information.

A discussion of the social aspects of physician-patient confidentiality would not be complete without attention to the impact of the information age. At present there are many online theaters of social communication, like YouTube, Facebook, LinkedIn, and the like, that remodel our ways of claiming, protecting, and enacting privacy. The indiscretions of burgeoning medical professionals for whom these forms of communication are second nature have led to concerns over inculcating new habits of careful information sharing. In a recent study by Bosslet et al. [13] of medical students, residents, and practicing physicians, practicing physicians were least likely to use social media, yet they were most likely to receive social-media "friend" requests from patients. A majority of this group did not think it was ethically advisable to form such online relationships—largely out of concern for confidentiality.

In the modern age of electronic health records, it may be technically possible to hack into any database. Records that, in the past, were protected mainly by lock and key, are still vulnerable. Still, the citadel of trust, privacy, and confidentiality in medicine is the doctor-patient relationship, the reciprocal promises and expectation of

experiences and truths revealed and suffering attended to. Hacking this "archive" is not a technical challenge, but would require moral failure that each physician can and should prevent in their privileged trust with patients.

References

1. Siegler M. Confidentiality in medicine- a decrepit concept. *N Engl J Med*. 1982;307(24):1518-1521.
2. Francis LP. Privacy and confidentiality: the importance of context. *Monist*. 2008;91(1):52-67.
3. Moskop JC, Marco CA, Larkin GL, Geiderman JM, Derse AR. From Hippocrates to HIPAA: privacy and confidentiality in emergency medicine--part i: conceptual, moral, and legal foundations. *Ann Emerg Med*. 2005;45(1):53-59.
4. Meer D, VandeCreek L. Cultural considerations in release of information. *Ethics Behav*. 2002;12(2):143-156.
5. O'Brien J, Chantler C. Confidentiality and the duties of care. *J Med Ethics*. 2003;29(1):36-40.
6. King NMP, Strauss RP, Churchill LR, Estroff SE, Henderson GE, Oberlander J. *The Social Medicine Reader, Volume 1: Patients, Doctors and Illness*. Durham, NC: Duke University Press; 2005:187.
7. Hunt L. Beyond cultural competence: applying humility to clinical settings. In: Estroff, S., Henderson, G. et al. *The Social Medicine Reader, Volume 2: Social and Cultural Contributions to Health Difference, and Inequality*. Duke University Press; 2005:134.
8. Bourke L, Sheridan C, Russell U, Jones G, DeWitt D, Liaw S. Developing a conceptual understanding of rural health practice. *Aust J Rural Health.* 2004;12(5):181-186.
9. Sankar P, Mora S, Merz JF, Jones NL. Patient perspectives of medical confidentiality: a review of the literature. *J Gen Intern Med*. 2003;18(8):659.
10. Sankar et al, 663.
11. Sankar et al, 665.
12. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall; 1963.
13. Bosslet GT, Torke AM, Hickman SE, Terry CL, Helft PR. The patient-doctor relationship and online social networks: results of a national survey. *J Gen Intern Med*. 2011;26(10):1168-1174.

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HISTORY OF MEDICINE

The Evolution of Confidentiality in the United Kingdom and the West

Angus H. Ferguson, MPhil, PhD

By its very nature medical practice involves the opening up of private lives to external scrutiny. The understanding that medical consultations are confidential encourages openness, trust, and frank disclosure of all possibly relevant information between patient and doctor. This in turn facilitates efficient and effective diagnosis, prognosis, and treatment of illness and disease. Confidentiality is therefore an integral element of the patient-doctor relationship, playing a vital role in the primary healing purpose of the profession. As such, it can be considered essential to the moral nature of the practice [1].

However, medicine is not practiced in a vacuum. The boundaries of confidentiality have not been determined solely by the nature of the patient-doctor relationship. Rather, the concept has been affected by a variety of external factors. Historical research into the evolution of approaches to medical confidentiality reveals an enduring ideal that has been interpreted through a variety of theoretical lenses and influenced by more pragmatic concerns.

In terms of theory, the debate has drawn upon consequentialist arguments, deontological ideals of professional duty, and concepts of honor, etiquette, human rights, and bioethics. Specific pragmatic concerns change with the sociohistoric context in which such debates take place, but often incorporate legal constraints, professional interests, health care policy agendas, and the broader sociopolitical environment, including the contested balance between individual liberty and communitarian objectives. What follows is a brief overview of some of these debates and their contexts.

Ancient codes of ethics often implied exceptions to the obligation of confidentiality in general terms. An obvious example is the relevant section within the Hippocratic Oath: “whatever I see or hear in the lives of my patients, whether in connection with my professional practice or not, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private” [2]. While highlighting the long-standing recognition of the importance of confidentiality to medical practice, the qualification that confidentiality covered only those things “that ought not to be spoken of outside” suggests that the obligation of confidentiality was not considered absolute. Over time, and in response to particular concerns, exceptions came to be more specifically defined.

Writing in the late eighteenth century, the British physician and moralist John Gregory noted that doctors, by the nature of their work, had access to the private homes and lives of patients—often seeing them at their most vulnerable. In such circumstances, patients might disclose deeply private thoughts or act in uncharacteristic ways. With this in mind, Gregory emphasized "how much the characters of individuals, and the credit of families, may sometimes depend on the discretion, secrecy, and honor of a physician" [3]. Gregory's point is echoed in Thomas Percival's assertion that "secrecy and delicacy when required by particular circumstances, should be strictly observed….The familiar and confidential intercourse, to which the faculty are admitted in their professional visits, should be used with discretion, and with the most scrupulous regard to fidelity and honour" [4].

While the writings of Gregory and Percival, regarded as two of the founding fathers of modern medical ethics, underscore the enduring status of confidentiality as an ethical ideal in medical practice, their emphasis on honor also illustrates how the debate has been shaped by more historically contingent factors. Operating in a competitive private marketplace, elite physicians in eighteenth-century Britain sought to present themselves as honorable gentlemen in order to secure the trust and favor of wealthy upper-class clients.

It was within this context that an elite surgeon challenged the law's authority to demand evidence from a medical witness during the trial of the Duchess of Kingston for the crime of bigamy in 1776 [5]. The House of Lords, in which the trial took place, rejected the surgeon's appeal for medical privilege, pointing out that any disclosure of information made at the request of a court of law would not be regarded as contravening the boundaries of professional trust or honor. Detailed analysis suggests that this precedent was set on a false premise, but, despite subsequent challenges, the denial of medical privilege has been maintained in English law [5].

Given its legal basis, attitudes to medical privilege can vary across regional and national jurisdictions—as well as between a single jurisdiction's civil and criminal law. Although courts of law have recognized the importance of confidentiality to effective medical practice, they have, with few exceptions, routinely ruled that the ends of justice supersede doctors' obligation of professional secrecy [6]. In most criminal law jurisdictions, judicial rejection of medical privilege has been one area in which exceptions to the rule of confidentiality have become crystallized.

Over the course of the nineteenth and early twentieth centuries, an era of international industrial and military competition, there was a shift from relatively unbridled freedom of the individual in the private medical marketplace to greater emphasis on the collective. This led some doctors to feel pulled between competing obligations to patient confidentiality and collective welfare. As the common law continued to reject calls for medical privilege, statute law and public health policy demands placed new emphasis on the value of medical information beyond its original function in the patient-doctor relationship. In Britain, this emphasis reflected

growing state interest in the health of the population as a key resource to the country's economic and military competitiveness [7].

The emerging specialty of public health brought with it new categories of doctors, such as medical officers of health for municipal authorities, whose agenda reversed the priorities of the private practitioner, rebalancing individual and communitarian interests in favor of collective welfare and "herd protection." Public health legislation required doctors to report cases of contagious and infectious diseases [7]. The rise of public health medicine symbolized the growing importance of a collective health agenda, but medical officers of health were only one example of a growing number of medical roles that emphasized, and began to redefine, physicians' dual obligations to patients and third-party interests. Military physicians, for instance, had an obligation to share information with the chain of command in cases of malingering or when a serviceman posed a risk to himself, his unit, or military objectives [8].

Changes in the organization and funding of health care increasingly meant that private practitioners were drawn into dual loyalty commitments. In Britain, the establishment of the National Health Insurance scheme in 1911, with its associated medical benefits for restricted groups of workers, blurred the surveillance and therapeutic roles of medical practitioners. With workers, employers, and the state all contributing to the cost of health care insurance, each had an interest in the doctor's assessment of an insured patient who sought paid absence from work [9].

Changes within medicine itself also caused problems for the traditional model of medical confidentiality. Growing specialization in medical knowledge and training ensured that, as the twentieth century progressed, patient care was increasingly carried out by combinations of health care specialists and medical institutions rather than an individual doctor. The "patient-doctor" relationship was gradually supplanted by a "patient-health care services" relationship, calling into question the continued relevance of the confidentiality concepts based on the former.

Computers and information technology have facilitated the necessary storage and sharing of patients' information across health care teams but simultaneously raised concerns about data security and accessibility. Changes in the social context of medical practice (not least the entry of women into the medical profession) entail that the eighteenth-century notion of gentlemanly honor stressed by Gregory and Percival no longer figures in debates on medical confidentiality. Instead, current discussions often draw on the discourses of patient rights [10] and bioethics [11], reflecting the contemporary prominence of human rights and the emphasis on patient autonomy in the (post)modern medical world.

The growing recognition and understanding that individual and collective health and welfare are influenced by a variety of social, economic, environmental, and genetic factors points to the importance of collaborative interdisciplinary medical research and integrated, inter-agency approaches to health care policy. The success of such

schemes depends on the correlation of information drawn from an ever-widening range of sources, in a legal context that stresses institutions' responsibilities to ensure that the personal data they hold is not misused. Potential conflicts between, on the one hand, patients' rights to privacy and respect for individuals' autonomy regarding how their personal information is used, and, on the other, the effectiveness of health care policy and medical research, ensure that the boundaries of medical confidentiality continue to pose challenges in the twenty-first century.

It is unlikely that the boundaries of confidentiality were regarded as absolute. Rather, as outlined above, general exceptions to the rule of confidentiality, implied in somewhat vague terms, have become more explicitly defined in response to specific concerns in particular times and places. While research has started to shed light on these historically contingent details, in so doing it has illuminated two enduring features. One is that medical confidentiality has always been regarded as an integral element of good medical practice. The other is that its boundaries have been the subject of perpetual challenge and debate.

References

1. Pellegrino ED. The moral foundations of the patient-physician relationship: the essence of medical ethics. In: Lounsbury DE, Bellamy RF, eds. *Military Medical Ethics*. US Office of the Surgeon General and Department of the Army; 2003:3-21. http://www.bordeninstitute.army.mil/published_volumes/ethicsVol1/ethicsVol1.html. Accessed August 9, 2012.
2. National Institutes of Health History of Medicine Division. Greek medicine: "I swear by Apollo physician…": Greek medicine from the gods to Galen. http://www.nlm.nih.gov/hmd/greek/greek_oath.html
3. Gregory J. *Lectures on the Duties and Qualifications of a Physician*. London: W. Strahan; 1772:26.
4. Percival T. *Medical Ethics; or a code of institutes and precepts, adapted to the professional conduct of physicians and surgeons*. Manchester, UK: S. Russell; 1803:390.
5. Ferguson AH. The lasting legacy of a bigamous duchess: the benchmark precedent for medical confidentiality. *Soc Hist Med*. 2006;19(1):37-53.
6. Ferguson AH. Exploring the myth of a Scottish privilege: a comparison of the early development of the law on medical confidentiality in Scotland and England. In: Freeman M, Gordon E, Maglen K, eds. *Medicine, Law and Public Policy in Scotland c.1850-1990*. Dundee, UK: Dundee University Press; 2011:125-140.
7. Ferguson AH. Speaking out about staying silent: an historical examination of medico-legal debates over the boundaries of medical confidentiality. In: Goold I, Kelly C, eds. *Lawyers' Medicine: The Legislature, The Courts & Medical Practice, 1760-2000*. Oxford, UK: Oxford University Press; 2009:99-125.
8. Ferguson AH. Medical confidentiality. In: Carrick D, Gross M, eds. *Military Medical Ethics for the 21st Century*. London: Ashgate Publishing; 2013.

9. Pickstone JV. Production, community and consumption: the political economy of twentieth-century medicine. In: Cooter R, Pickstone JV, eds. *Medicine in the Twentieth Century*. Amsterdam: Harwood Academic Publishers; 2000.
10. British Medical Association. *The Medical Profession & Human Rights: Handbook for a Changing Agenda*. London: Zed Books; 2001.
11. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 5th ed. Oxford: Oxford University Press; 2001.

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Virtual Mentor
American Medical Association Journal of Ethics
September 2012, Volume 14, Number 9: 743-750.

Suggested Readings and Resources

American Health Information Management Association. Auditing copy and paste. *J Am Health Inf Management Assoc*. 2009;80(1):26-29. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_042416.hcsp?dDocName=bok1_042416. Accessed August 10, 2012.

American Health Information Management Association. Copy functionality toolkit; 2008:4. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_042564.pdf#xml=http://library.ahima.org/xpedio/idcplg?IdcService=GET_XML_HIGHLIGHT_INFO&QueryText=%28cut+copy+and+paste%29%3Cand%3E%28xPublishSite%3Csubstring%3E%60BoK%60%29&SortField=xPubDate&SortOrder=Desc&dDocName=bok1_042564&HighlightType=PdfHighlight. Accessed August 10, 2012.

American Health Information Management Association. Mobile device security (updated). *J Am Health Inf Management Assoc*. 2012;83(4):50. http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_049463.hcsp?dDocName=bok1_049463. Accessed August 10, 2012.

American Health Information Management Association. The 10 security domains (updated). *J Am Health Inf Management Assoc*. 2012;83(5):50.

American Medical Association. Opinion 5.05 - Confidentiality. *Code of Medical Ethics*. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion505.page. Accessed August 14, 2012.

American Medical Association. Opinion 5.051 - Confidentiality of medical information postmortem. *Code of Medical Ethics*. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion5051.page. Accessed August 14, 2012.

American Medical Association. Principles of medical ethics. In: *Current Opinions of the Judicial Council of the American Medical Association*. Chicago: American Medical Association; 1981:ix.

Amoroso PJ, Middaugh JP. Research vs. public health practice: when does a study require IRB review? *Preventive Med*. 2003;36:250-253.

Andreassen CS, Torsheim T, Brunborg GS, Pallesen S. Development of a Facebook Addiction Scale. *Psychol Rep*. 2012;110(2):501-517.

Armstrong v United States, 364 US 40, 49 (1960).

Autopsies; confidentiality of photographs and video and audio recordings; exemption, Fla Stat section 406.135(4)(a)-(c).

Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 5th ed. Oxford: Oxford University Press; 2001.

Bell A, Parchomovsky G. The hidden function of takings compensation. *Virginia Law Rev*. 2010;96:1673-1725.

Berg J. Grave secrets: legal and ethical analysis of postmortem confidentiality. *Conn Law Rev*. 2001;34:81-122.

Boonstra H, Nash E. Minors and the right to consent to health care. *Issues Brief (Alan Guttmacher Inst)*. 2000;(2):1-6.

Bosslet GT, Torke AM, Hickman SE, Terry CL, Helft PR. The patient-doctor relationship and online social networks: results of a national survey. *J Gen Intern Med*. 2011;26(10):1168-1174.

Bourke L, Sheridan C, Russell U, Jones G, DeWitt D, Liaw S. Developing a conceptual understanding of rural health practice. *Aust J Rural Health.* 2004;12(5):181-186.

British Medical Association. *The Medical Profession & Human Rights: Handbook for a Changing Agenda*. London: Zed Books; 2001.

Brody H. *The Healer's Power*. New Haven, CT: Yale University Press; 1993.

Calabresi G, Melamed AD. Property rules, liability rules, and inalienability: one view of the cathedral. *Harvard Law Rev*. 1972;85(6):1089-1128.

Cameron C. Not getting to yes: why the media should avoid negotiating access rights. *Thomas Cooley Law Rev*. 2007;24(2):237-262.

Casarett D, Karlawish J, Andrews E, Caplan A. Bioethical issues in pharmacoepidemiologic research. In: Strom BL, ed. *Pharmacoepidemiology*. 4th ed. Chicester, UK: John Wiley & Sons; 2005: 597.

Castro CM, et al. Babel babble: physicians' use of unclarified medical jargon with patients. *Am J Health Behav*. 2007;31 Suppl 1:S85-S95.

Centers for Disease Control and Prevention. HIPAA privacy rule and public health. *MMWR Morb Mortal Wkly Rep*. 2003;52:1-20. http://www.cdc.gov/mmwr/pdf/other/m2e411.pdf. Accessed July 15, 2012.

Claeys ER. Takings, regulations, and natural property rights. *Cornell Law Rev*. 2003;88(6):1549-1671.

Disclosure of genetic information; exceptions. Or Rev Stat section 192.539 (2011).

Edelstein L. The Hippocratic Oath: text, translation and interpretation. In: Temkin O, Temkin CL, eds. *Ancient Medicine: Selected Papers of Ludwig Edelstein*. Baltimore, MD: The Johns Hopkins Press; 1967:6.

English A, Ford CA. The HIPAA privacy rule and adolescents: legal questions and clinical challenges. *Perspect Sex Reprod Health*. 2004;36(2):80-86.

Evans BJ. Ethical and privacy issues in pharmacogenomic research. In: Macleod HL, ed. *Pharmacogenomics: Applications to Patient Care*. 2nd ed. Lenexa, KS: American College of Clinical Pharmacy; 2009:313-338.

Evans BJ. Much ado about data ownership. *Harvard J Law Tech*. 2012;25(1):69-130.

Ferguson AH. Exploring the myth of a Scottish privilege: a comparison of the early development of the law on medical confidentiality in Scotland and England. In: Freeman M, Gordon E, Maglen K, eds. *Medicine, Law and Public Policy in Scotland c.1850-1990*. Dundee, UK: Dundee University Press; 2011:125-140.

Ferguson AH. Medical confidentiality. In: Carrick D, Gross M, eds. *Military Medical Ethics for the 21st Century*. London: Ashgate Publishing; 2013.

Ferguson AH. Speaking out about staying silent: an historical examination of medico-legal debates over the boundaries of medical confidentiality. In: Goold I, Kelly C, eds. *Lawyers' Medicine: The Legislature, The Courts & Medical Practice, 1760-2000*. Oxford, UK: Oxford University Press; 2009:99-125.

Ferguson AH. The lasting legacy of a bigamous duchess: the benchmark precedent for medical confidentiality. *Soc Hist Med*. 2006;19(1):37-53.

Fins JJ, Miller FG. Clinical pragmatism, ethics consultation, and the elderly patient. *Clin Geriatr Med*. 2000;16(1):71-81, ix.

Francis LP. Privacy and confidentiality: the importance of context. *Monist*. 2008;91(1):52-67.

Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall; 1963.

Greene AH. HHS steps up HIPAA audits: now is the time to review security policies and procedures. *J Am Health Inf Management Assoc*. 2011;82(10):58-59.

Gregory J. *Lectures on the Duties and Qualifications of a Physician*. London: W. Strahan; 1772:26.

Hall MA. Property, privacy, and the pursuit of interconnected electronic medical records. *Iowa Law Rev*. 2010;95(2):631-663.

Hart JF. Land use law in the early republic and the original meaning of the takings clause. *Northwestern Univ Law Rev*. 2000;94:1099-1156.

Health Insurance Portability and Accountability Act of 1996, Pub L No 104-191, 110 Stat 1936 (codified as amended in scattered sections of 18, 26, 29 and 42 USC).

HHS. Advanced notice of proposed rulemaking: human subjects research protections: enhancing protections for research subjects and reducing burden, delay, and ambiguity for investigators. *Fed Regist*. 2011;76:44512-44531. To be codified at 45 CFR parts 46, 160, 164, and 21 CFR parts 50, 56. https://www.federalregister.gov/articles/2011/07/26/2011-18792/human-subjects-research-protections-enhancing-protections-for-research-subjects-and-reducing-burden. Accessed August 9, 2012.

HHS. Basic HHS Policy for Protection of Human Subjects (Common Rule), 45 CFR part 46 subpart A (sections 46.101-46.124).

HHS. Security and privacy, 45 CFR section 164.

Hodge JG, Gostin LO. Public health practice vs. research. Council of State and Territorial Epidemiologists; 2004:7. http://www.cste.org/pdffiles/newpdffiles/CSTEPHResRptHodgeFinal.5.24.04.pdf. Accessed July 15, 2012.

Hodge JG. An enhanced approach to distinguishing public health practice and human subjects research. *J Law Med Ethics*. 2005;33(1):125-140.

Huba N, Zhang Y. Designing patient-centered personal health records (PHRs): health care professionals' perspective on patient-generated data. *J Med Syst*. 2012 May 30 [epub ahead of print].

Hunt L. Beyond cultural competence: applying humility to clinical settings. In: Estroff, S., Henderson, G. et al. *The Social Medicine Reader, Volume 2: Social and Cultural Contributions to Health Difference, and Inequality*. Duke University Press; 2005:134.

Jacobson PD. Medical records and HIPAA: is it too late to protect privacy? *Minn Law Rev*. 2002;86(6):1497-1514.

Jureidini JN, Doecke CJ, Mansfield PR, Haby MM, Menkes DB, Tonkin AL. Efficacy and safety of antidepressants for children and adolescents. *BMJ*. 2004;328(7444):879-883.

King M. Physician duty to warn a patient's offspring of hereditary genetic defects: balancing the patient's right to confidentiality against the family member's right to know—can or should Tarasoff apply? *Quinnipiac Health Law J*. 2000;4(1):1-38.

King NMP, Strauss RP, Churchill LR, Estroff SE, Henderson GE, Oberlander J. *The Social Medicine Reader, Volume 1: Patients, Doctors and Illness*. Durham, NC: Duke University Press; 2005:187.

Lehrer JA, Pantell R, Tebb K, Shafer MA. Forgone health care among U.S. adolescents: associations between risk characteristics and confidentiality concern. *J Adolesc Health*. 2007;40(3):218-226.

Liaison Committee on Medical Education. Functions and structure of a medical school: standards for accreditation of medical education programs; May 2011. http://www.lcme.org/functions.pdf. Accessed June 27, 2012.

Liaw T, Lawrence M, Rendell J. The effect of a computer-generated patient-held medical record summary and/or a written personal health record on patients' attitudes, knowledge and behaviour concerning health promotion. *Fam Pract*. 1996;13(3):289-293.

Lo B, Parham L. The impact of web 2.0 on the doctor-patient relationship. *J Law Med Ethics*. 2010;38(1):17-26.

Meer D, VandeCreek L. Cultural considerations in release of information. *Ethics Behav*. 2002;12(2):143-156.

Merrill TW. The economics of public use. *Cornell Law Rev*. 1986;72:61-116.

Montgomery, K. *How Doctors Think: Clinical Judgment and the Practice of Medicine*. New York: Oxford University Press; 2005:49.

Moskop JC, Marco CA, Larkin GL, Geiderman JM, Derse AR. From Hippocrates to HIPAA: privacy and confidentiality in emergency medicine--part i: conceptual, moral, and legal foundations. *Ann Emerg Med*. 2005;45(1):53-59.

Nass SJ, Levit LA, Gostin LO eds.; Institute of Medicine Committee on Health Research and the Privacy of Health Info. *Beyond The HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research*. Washington, DC: National Academies Press; 2009. http://www.nap.edu/catalog/12458.html. Accessed August 8, 2012.

National Institute of Standards and Technology Computer Security Division. *An Introduction to Computer Security: The NIST Handbook*. U.S. Department of Commerce. Gaithersburg, MD: NIST; 1995:5. http://csrc.nist.gov/publications/nistpubs/800-12/800-12-html/index.html. Accessed August 10, 2012.

National Institutes of Health History of Medicine Division. Greek medicine: "I swear by Apollo physician…": Greek medicine from the gods to Galen. http://www.nlm.nih.gov/hmd/greek/greek_oath.html

O'Brien J, Chantler C. Confidentiality and the duties of care. *J Med Ethics*. 2003;29(1):36-40.

Odom-Wesley B, Brown D, Meyers CL. *Documentation for Medical Records*. Chicago: American Health Information Management Association; 2009:21.

Office for Human Research Protections. Guidance on research involving coded private information or biological specimens; Oct. 16, 2008. http://www.hhs.gov/ohrp/policy/cdebiol.html. Accessed July 15, 2012.

Office of the National Coordinator for Health Information Technology. *Guide to Privacy and Security of Health Information*; 2012:5. http://www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf. Accessed August 10, 2012.

Ormondroyd E, Moynihan C, Watson M, et al. Disclosure of genetics research results after the death of the patient participant: a qualitative study of the impact on relatives. *J Genetic Couns*. 2007; 16(4): 527-538.

Parmet WE. After September 11: rethinking public health federalism. *J Law Med Ethics*. 2002;30(2):201-211.

Pellegrino ED. The moral foundations of the patient-physician relationship: the essence of medical ethics. In: Lounsbury DE, Bellamy RF, eds. *Military Medical Ethics*. US Office of the Surgeon General and Department of the Army; 2003:3-21. http://www.bordeninstitute.army.mil/published_volumes/ethicsVol1/ethicsVol1.html . Accessed August 9, 2012.

Percival T. *Medical Ethics; or a code of institutes and precepts, adapted to the professional conduct of physicians and surgeons*. Manchester, UK: S. Russell; 1803:390.

Pickstone JV. Production, community and consumption: the political economy of twentieth-century medicine. In: Cooter R, Pickstone JV, eds. *Medicine in the Twentieth Century*. Amsterdam: Harwood Academic Publishers; 2000.

Rinehart-Thompson LA, Harman LB. Privacy and confidentiality. In: Harman LB, ed. *Ethical Challenges in the Management of Health Information*. 2nd ed. Sudbury, MA: Jones and Bartlett; 2006:53.

Rodwin MA. Patient data: property, privacy & the public interest. *Am J Law Med*. 2010;36(4):586-618.

Rognehaugh R. *The Health Information Technology Dictionary*. Gaithersburg, MD: Aspen; 1999:125.

Safer v Estate of Pack, 677 A2d 1188 (NJ Supp 1996).

Sankar P, Mora S, Merz JF, Jones NL. Patient perspectives of medical confidentiality: a review of the literature. *J Gen Intern Med*. 2003;18(8):659.

Siegler M. Confidentiality in medicine – a decrepit concept. *N Engl J Med*. 1982;307(24):1518-1521.

Snider DE Jr, Stroup DF. Defining research when it comes to public health. *Pub Health Rep*. 1997;112(1): 29-32.

Tarasoff v Regents of University of California. 17 Cal 3d 425, 131 Cal Rptr 14, 551 P2d 334.

Tasse A. Return of research results: how should research results be handled?: the return of results of deceased research participants. *J Law Med Ethics*. 2011;39(4):621-630.

Terilli S, Splichal SL. Public access to autopsy and death-scene photographs: relational privacy, public records, and avoidable collisions. *Comm Law Policy*. 2005;10(3):313-348.

The five states are Alaska, Colorado, Florida, Georgia, and Louisiana. Ram N. Assigning rights and protecting interests: constructing ethical and efficient rights in human tissue research. *Harvard J Law Tech*. 2009;23(1):141.

Todd JS. Report of the Ad Hoc Committee on the Principles of Medical Ethics [of the American Medical Association]. Unpublished report; 1979.

Tonkin A, Jureidini J. Wishful thinking: antidepressant drugs in childhood depression. *Br J Psychiatry*. 2005;187:304-305.

University of California settles HIPAA privacy and security case involving UCLA Health System facilities [news release]. Washington, DC: US Department of Health and Human Services; July 7, 2011.

http://www.hhs.gov/news/press/2011pres/07/20110707a.html. Accessed August 10, 2012.

University of North Carolina School of Medicine. Article 5: Responsibilities of medical students. http://www.med.unc.edu/md/governance/policies/files/Article5ResponsibilitiesofMedicalStudents2012220.pdf. Accessed August 9, 2012.

US Department of Health and Human Services Office for Civil Rights. UCLA Health System settles potential HIPAA privacy and security violations. http://www.hhs.gov/ocr/privacy/hipaa/news/uclahs.html. Accessed August 10, 2012.

US Department of Health and Human Services Office for Civil Rights. Resolution agreement [UCLA Health System]. http://www.hhs.gov/ocr/privacy/hipaa/enforcement/examples/UCLAHSracap.pdf. Accessed August 10, 2012.

US Department of Health and Human Services Office for Civil Rights. Health information privacy: frequently asked questions: how can family members of a deceased individual obtain the deceased individual's protected health information that is relevant to their own health care?. http://www.hhs.gov/ocr/privacy/hipaa/faq/right_to_access_medical_records/222.html. Accessed July 6, 2012.

US Food and Drug Administration. Medication guide: antidepressant medicines, depression and other serious mental illnesses, and suicidal thoughts or actions. http://www.fda.gov/downloads/Drugs/DrugSafety/InformationbyDrugClass/ucm100211.pdf. Accessed June 3, 2012.

Veatch RM. *A Theory of Medical Ethics*. New York: Basic Books; 1981.

Veatch RM. *Hippocratic, Religious, and Secular Medical Ethics: The Points of Conflict*. Washington, DC: Georgetown University Press; in press.

Warren SD, Brandeis LD. The right to privacy. *Harvard Law Rev*. 1890;4:193.

Wibe T, Helleso R, Slaughter L, Ekstedt M. Lay people's experiences with reading their medical record. *Soc Sci Med*. 2011;72(9):1570-1573.

Williams IW, Kennedy BS. Texting tendinitis in a teenager. *J Fam Pract*. 2011;60(2):66-67.

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