

# Ethics and the Law

Doctors practice in an environment of increasing contractual and regulatory complexity in which their moral obligations to patients may collide head-on with legal or societal obligations.

## Chapter in Brief:

- ▲ *Privacy requirements outlined in the Health Insurance Portability and Accountability Act (HIPAA) may sometimes compromise the ethical principle of patient-welfare primacy.*
- ▲ *Ethical and practical concerns about patient privacy have become more complicated in the Internet age. As more physicians contribute to consumer Websites or start their own blogs, their activities pose ethical and legal problems.*
- ▲ *Studies have shown that up to 50 percent of patients do not understand or do not retain the information they receive in consent documents.*
- ▲ *Rising healthcare costs are compelling insurers and government payers to adopt cost-containment strategies and utilization controls that often find physicians smack in the middle between patients and their health plans.*

To the extent possible, physicians should strive to keep the patient's interests foremost, medical ethicists advise, and should seek counsel when a legal obligation may be at odds with the patient's interest. At that point, physicians will have to rely on their best judgment, keeping in mind that their obligation to the patient is always paramount, except possibly in cases when a patient has threatened to harm others.

“We should never turn to lawyers to ask them what's right—

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only what's legal," says Faith T. Fitzgerald, MD, assistant dean of humanities and bioethics at the University of California-Davis Health System in Sacramento. "The law is not the same thing as ethics, and it's important for physicians to remember that law varies from time to time and place to place. Sometimes laws can be wrong or unethical."

### **Privacy Issues in the Internet Age**

Most ethical oaths and creeds require physicians to keep patient information confidential, but this can be difficult in light of regulatory and reporting requirements. For example, while physicians or treating institutions legally "own" the medical record, information in the chart is actually the patient's property. That fact may spark ethical dilemmas when a patient either does—or doesn't—want information disclosed to other parties, or when a health plan or institution's request for information counters a patient's desire for confidentiality. Requirements of the Health Insurance Portability and Accountability Act (HIPAA) have added at least another layer to concerns about privacy. Increased quality improvement (QI) projects in physician practices have complicated the issue even further.

In their health plan contracts, physicians often must agree to participate in quality improvement activities as a condition of credentialing. If a patient requests confidentiality of certain information about a disease or illness that the QI activity involves, the physicians "could find themselves caught in the middle," says James Rohack, MD, president-elect of the American Medical Association. "This is an issue physicians are struggling with now."

HIPAA laws, which were enacted to protect patient privacy in this world of health-information databases and the near-instant access to patients' sensitive information that the Internet affords, are creating ethical conflicts at the point of care. Endocrinologist Frank Davidoff, MD, executive editor of the Boston-based Institute for Healthcare Improvement's publications section, who has written frequently about issues involving QI and clinical ethics, acknowledges physicians' concerns about associated privacy issues. "This really is affecting physicians' lives in that most of what's being done in QI involves patients directly and

requires obtaining information from their charts,” he says. “The HIPAA officials have indicated that there are a variety of ways to obtain appropriate waivers from HIPAA requirements for research,” he adds, acknowledging that HIPAA should not stand in the way of conducting improvement projects.

“But HIPAA is a tricky business, and physicians who are involved in improvement projects—little ones or midsize ones—need to be aware that there’s an ethical dimension and a legal dimension,” says Dr. Davidoff, former editor of *Annals of Internal Medicine*.

HIPAA requirements are impacting medical practice in other ways, too. The dauntingly complex HIPAA privacy requirements, which require physicians and others in healthcare to safeguard protected health information (PHI), may sometimes compromise the ethical principle of patient-welfare primacy. As a patient travels from one healthcare setting to the next, for example, a delay in the transfer of important patient informa-

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tion—or a refusal to divulge the patient’s presence—may actually harm the patient if care continuity is compromised or patients are isolated. In several cases in recent years, family members who may have played an important role in an inpatient’s care have been denied access to the patient when HIPAA rules were applied in an overzealous manner.

“In addition to limiting communication for physicians and patients, HIPAA privacy rules create a real and potentially harmful impediment to treatment and may limit how patients deal with their illnesses,” writes Alaska internist Richard Neubauer, MD, in his August 2006 article, “Paranoia Over Privacy,” published in *Annals of Internal Medicine*.

Dr. Neubauer, a frequent contributor to publications and position statements on ethical issues in clinical practice, is writing

from firsthand experience. When he was diagnosed with a serious illness (primary amyloidosis) and transferred to New York City for an autologous stem-cell transplantation procedure, Dr. Neubauer got direct experience with privacy regulations. “My concern is that worries about privacy issues could prevent patients from receiving the support they need—or could actually impede their care,” he writes.

At the same time, ethical and practical concerns about patient privacy are valid, especially as the Internet both speeds dissemination of information and poses confidentiality threats. Many well-meaning physicians have begun participating in consumer Websites that offer patients a means of obtaining basic (or even specific) guidance on disease treatment and management. Others have launched their own Web logs (blogs) to share details on their practice lives and, frequently, their perspectives on interactions with patients. Both activities pose ethical problems and potential legal ones, too, if the physician’s identity is disclosed and, by extension, the patient’s as well.

A study published in the July 2008 *Journal of General Internal Medicine* illustrates this emerging conflict. In a 2006 study, lead researcher Tara Lagu, MD, MPH, and colleagues at the University of Pennsylvania reviewed 271 blogs written by physicians or nurses. Nearly 60 percent contained enough information to enable readers to identify their authors (even though 65 percent of the bloggers did not use their real names). More important, about 42 percent included descriptions of interactions with individual patients. Nearly one-fifth (17 percent) of the blogs included sufficient information for patients to identify their doctors or themselves.

Many of the blogs portrayed patients in a negative light, Dr. Lagu notes: “While many medical blogs provide valuable information to the public . . . others pose a threat to patient privacy and have the potential to threaten the integrity of the medical profession,” she writes, adding that physician-organization guidance on the issue is sorely needed.

The vast majority of physicians, of course, are not writing blogs or participating in communication venues that compromise either their ethics or patients’ confidentiality. Attempting to both meet the letter of the law and address the real needs of patients

in honoring confidentiality can still pose dilemmas, however. The following basic guidelines, based on those published by physician organizations, serve as a good starting point:

- Don't release patients' PHI without their written consent unless disclosure is necessary to protect others.
- To the extent practically possible, limit discussion of patients and their individual care to the patient visit unless prior permission has been granted to discuss the patient's condition.
- Be cognizant of state and other laws governing adolescent patients' rights to medical record confidentiality and their rights regarding treatment consent.

### Informed Consent in a Complex Environment

Informed consent is another area that lies squarely at the intersection of legal and ethical issues. The doctrine of informed consent to receive medical care, rooted in common-law tort doctrine and constitutionally granted privacy rights, has remained an eth-

#### What Constitutes PHI

Physicians who are trying to comply with HIPAA's privacy regulations should keep in mind that PHI is determined not by the content of the intended communication but rather by whether the information includes identifying elements that link it to a specific individual. Those identifiers include the following:

Name	Full-face photographs
Social Security Number	Biometric ID – finger, voice prints
Medical Record number	Health Plan number
Geographic location, except for state	Account number
All dates, except for year	Driver's license number
Age > 89	Vehicle identification
Phone number	Device numbers
Fax number	URLs and IP address
E-mail address	Any other unique number or code

ically contentious area for three decades since it appeared in the wake of research-subject abuses and considerable subsequent efforts to address those abuses through an ethical framework.

Few physicians would dispute their moral, ethical, and legal responsibility to fully disclose the risks, objectives, and expected outcomes of any treatment, as well as the treatment alternatives—in a manner understandable to the patient. But the effectiveness of informed-consent exchanges has been seriously questioned in recent years, as studies have shown that up to 50 percent of patients do not understand or do not retain the information they receive in consent documents. That reality has prompted some physicians to refer to the practice as the “myth of informed consent.”

Fabrice Jotterand, PhD, who teaches ethics in the department of psychiatry at the University of Texas Southwestern Medical Center in Dallas, acknowledges the challenges that clinicians and researchers face in trying to ensure that patients are adequately informed. “Patient consent is a huge issue now,” says Dr. Jotterand, especially in situations where patients with treatment-resistant disease or life-threatening illnesses sign on for experimental treatments. “Do patients who have no alternative really read 20 pages of informed consent when they are desperate?” he asks. Even under the best of circumstances, many consent documents are dauntingly complex and are written at reading levels considerably higher than that of the average patient.

Informed consent in the academic-research setting typically presents more ethical challenges than in the community practice environment, especially when the treatment under consideration is highly experimental. But physicians who engage in office-based research or perform procedures in the office rather than the inpatient setting face such challenges as well. In either setting, experts at the AMA and other organizations advise, physicians who wish to ensure their patients (or surrogates) are equipped to make healthcare decisions should make certain that they accomplish the following tasks:

- Provide explanations in understandable language (ideally in the patient’s first language) of the nature of the ailment or condition; the proposed diagnostic steps and/or treatment(s) and the probability of their success; the existence and nature of the risks

involved; and the existence, potential benefits, and risks of recommended alternative treatments. The latter should address the “no-treatment” option as well.

- Assess the patient’s understanding of the information that has been provided (a step many healthcare professionals fail to take, beyond merely asking if the patient has understood).
- Assess, even if only tacitly, the patient’s or surrogate’s capacity to make the necessary decision(s).
- Assure, to the extent possible, that the patient is free to choose among the medical alternatives.

The AMA urges physicians, whenever possible, to complete the informed-consent process and conversation before PHI is used for any purpose. (The federal Patient Self-Determination Act, or PSDA, requires that healthcare institutions inform patients in advance about policies with respect to any applicable rights regarding consent to and refusal of treatment, and execution of advance directives.)

Of course, it is sometimes difficult to assess a patient’s understanding of the information provided, even when an extensive conversation has ensued and a patient has asked numerous questions, notes Dr. Fitzgerald. In such cases, it’s reasonable for the physician to offer assistance in decision-making. “It’s important to honor patients’ autonomy, but doctors should also be willing to give advice when it’s requested,” she says.

How can physicians know when they have offered enough detail about a decision, thereby honoring their ethical obligation to obtain informed consent? Following are three standards suggested in the medical ethics and law literature:

**Reasonable physician standard: What would a typical physician say about this intervention?** This standard allows the physician to determine what information is appropriate to disclose, but its focus is on the physician and may not be sufficient to meet the patient’s needs.

**Reasonable patient standard: What would the average patient need to know to be an informed participant in the decision?** This standard focuses on considering how much a patient would need to know in order to understand the decision at hand.

**Subjective standard: What would this patient need to**

**know and understand in order to make an informed decision?** This standard represents the ideal—individualizing each informed-consent encounter—but may be challenging to incorporate into daily practice because of the effort required to tailor the information.

Most states have either enacted legislation or relied upon legal cases to determine the required standard for informed consent. Many states have adopted the “reasonable patient standard.”

### **Caught in the Middle**

Whether they have taken a formal oath or not, most physicians concur that they have an ethical obligation to treat all patients equally and with dignity, to relieve their suffering, and to act in patients’ interests, not their own, when advocating for appropriate resources. Most also agree that physicians should be good stewards of healthcare resources to the extent that they are able to direct or influence use of those resources.

Meeting those ethical obligations is easier said than done in an era when competing forces abound. Rising healthcare costs are compelling insurers and government payers to adopt cost-containment strategies and utilization controls that often find physicians in the middle between patients and their health plans. As insured patients assume an ever-increasing share of their healthcare costs, physicians are often asked to help patients make difficult decisions about which care to pursue and which to forgo or postpone. And as the number of uninsured patients rises and the safety net is stretched thin, physicians face a long-standing ethical challenge that has taken on new dimension: deciding which and how many patients they will treat when there is little or no likelihood of payment, especially as practice-overhead costs increase.

“It’s not physicians’ job to solve the [uninsured] problem, but to acknowledge it ... and cooperate in solving it,” contends Mary Ann Baily, PhD, a research scholar at The Hastings Center, an independent, nonprofit bioethics research institute in Garrison, N.Y. “It would be easier to be a doctor if there were better guidance on this, and a system in which cost was contained in an acceptable manner instead of crudely, by dumping people out. A lot of the ethical problems physicians find most troubling would

## Principles for Expert Witness Duty

Physicians who are called upon to serve as expert witnesses in lawsuits and court cases involving possible medical malpractice or medical care that resulted in patient harm may find it difficult to retain objectivity and avoid conflicts.

One helpful resource is the American College of Surgeons's expert witness affirmation, excerpted below:

As a member of the medical profession ... I affirm my duty, when giving evidence or testifying as an expert witness, to do so solely in accordance with the merits of the case. Furthermore, I declare that I will uphold the following professional principles in providing expert evidence or expert witness testimony.

1. I will always be truthful.
2. I will conduct a thorough, fair, and impartial review of the facts and medical care provided, not excluding any relevant information.
3. I will provide evidence or testify only in matters in which I have relevant clinical experience and knowledge in the areas of medicine that are the subject of the proceeding.
4. I will evaluate the medical care provided in light of generally accepted standards, neither condemning performance that falls within generally accepted practice standards nor endorsing or condoning performance that falls below these standards.
5. I will evaluate the medical care provided in light of the generally accepted standards that prevailed at the time of the occurrence.
6. I will provide evidence or testimony that is complete, objective, scientifically based, and helpful to a just resolution of the proceeding.
7. I will make a clear distinction between a departure from accepted practice standards and an untoward outcome.
8. I will make every effort to determine whether there is a causal relationship between the alleged substandard practice and the medical outcome.
9. I will submit my testimony to peer review, if requested by a professional organization to which I belong.
10. I will not accept compensation that is contingent upon the outcome of the litigation.

*Source: American College of Surgeons, Chicago, Ill. Accessible at [www.facs.org](http://www.facs.org).*

not be problems if we had a different system. But physicians have some responsibility to help figure out how to do this.”

In addition, many physicians are understandably torn about such issues as deciding how many Medicaid patients they should accept when the reimbursement likely won't cover their costs of caring for those individuals. Ethicists generally support the fair-share principle espoused by the AMA and other groups. That principle involves assessing the problem collectively within the physician community and asking individual physicians to commit to accepting a certain number of the patients—based on the nature of the physician's practice, specialty, and other factors such as space or staffing constraints.

Dr. Fitzgerald concurs with Dr. Baily that most ethical creeds, including the modern ones, do not recognize the realities of physicians' practice lives today. Physicians are sworn to keep individual patients' interests first, but also to conserve resources and protect humanity. “You can do one or the other, but you can't do both,” Dr. Fitzgerald says, “because caring for the individual—particularly the old, sick, and infirm—by necessity prolongs the drain on the commonwealth.”

That forces physicians to choose their position, in the often indelicate balancing act of advocating for individual patients, “which literally costs the system more,” Dr. Fitzgerald says, while feeling simultaneously obliged to ensure appropriate allocation of scarce resources.

“It's no wonder, then, that patients ask now: ‘Doctor, are you representing the system or me?’” she says.

Despite the conflicts swirling about them, physicians are well advised, Dr. Fitzgerald contends, to adhere to two basic principles and practices that she sums up as follows:

- If the physician believes something is obstructive to the patient's health, he or she has to fight it.
- Gender and racial disparity—or any kind of disparity—is an issue of social justice and ethics; physicians can never justify discrimination.

“Things are always changing, so it's important to keep the core,” Dr. Fitzgerald advises, when one is working through ethical dilemmas.

Many groups are working to identify and address care dispar-

ities in the big picture of healthcare delivery, but individual physicians can best honor their ethical responsibility in that regard by using a systematic approach, suggests Timothy Ferris, MD, MPhil, MPH, assistant professor of medicine and pediatrics at Harvard Medical School and the Institute for Health Policy in Boston. “The important thing about preventing [care] disparities is to ensure that if you put performance improvements in your practice, you don’t do things differently for different groups of patients,” says Dr. Ferris, whose research focuses on ethical issues in care delivery. “It really comes down to that.”

### **End-of-life Care**

Nowhere are resource questions more wrenching than at the end of life, when physicians may face pressure from patients’ families at one end and their institutions at the other. “Some of the dilemmas relate more to issues of control in that we have much more we can do now for patients—especially in oncology and cardiology,” says oncologist Ezekial Emanuel, MD, PhD, chair of the National Institutes of Health Department of Bioethics in Bethesda, Md. “So the dilemma of when to stop [active treatment] and bring in the palliative [care staff] has become much more complicated and murky.”

Giving patients another course of chemotherapy that may keep them alive an extra month, Dr. Emanuel explains, is more common today than it was a decade ago. “We’re seeing this in other fields as well. Cardiologists, for example, can ‘spin out’ their heart-failure patients,” he says, not just months but possibly years. “It’s complicated [to determine] when enough is enough—and physicians don’t want to have that conversation.”

But that conversation is one in which physicians often find themselves these days, and the associated ethical issues are immensely complex, according to Dr. Ferris.

“It’s a real social dilemma,” says Dr. Ferris. “It’s a conversation between—whether they’re in the room or not—generalists and specialists, among generalists, specialists, and patients—and between all of the above and family members.”

Dr. Ferris illustrates the conundrum with a common situation: The daughter entrusted with healthcare decisions for her 90-year-old father with terminal cancer and advanced lung disease

struggles to decide whether her father should be reintubated if needed. Doing so might extend his life but could worsen his quality of life.

“Family members often experience guilt, if they appear to not be doing absolutely everything for their parent,” he says. “That’s why decisions about end-of-life care are usually much easier with patients themselves than with family members.”

Some physicians recognize the difficult position the family caregiver is in and may not offer options they think won’t be productive, as a way of relieving—or at least reducing—the guilt factor. “There’s that ethic—don’t offer them things, like the third round of chemo, for example, or some technology solution with a marginal chance of benefit,” he says. Other physicians are inclined to simply lay all of the options on the table, even if it’s a dizzying and confusing array to the family member.

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As Dr. Ferris points out, doctors may explain to the patient or family member, “This is everything we can do, and this is the benefit,” but, he says, “The doctors often don’t talk about the downside risks of the ‘everything.’”

In such situations the palliative care physician may be “on the other side of the fence” from the oncologist, Dr. Ferris says. “The palliative care doctor says putting the decision burden on the family member when the patient will likely not survive another three months is unfair because they are not in a position to defer anything unless they are particularly enlightened,” he says. “There’s too much guilt about that for someone taking care of a parent.”

On the other hand, Dr. Ferris explains, the ethics of the oncologist may be that an extra few weeks or months of life are worth the potential downside. “I have had many patients who have been very grateful for that, for the technology, because it

allowed them time to say goodbye,” Dr. Ferris says. Those discussions are of necessity highly personalized and very time consuming, and require a certain skill set, he adds.

On the most basic level, physicians should help their patients near the end of life with decisions, not simply provide the options, Dr. Fitzgerald advises. “Abandoning patients to their autonomy—where doctors give information but don’t help with decisions—is terrible for some people,” she says. “They want help and advice. They’ve never died before.”

At the other end of the spectrum, Dr. Fitzgerald adds, the physician should honor the decisions patients make about end-of-life treatment even when those decisions run counter to the physician’s views. “If you are going to honor autonomy, that means honoring the decision patients make when they flout your opinion,” she says.

When physicians find themselves embroiled in a family conflict about a patient’s treatment near the end of life, it behooves them to look not only at their ethical responsibilities to the patient, but also at the relationship dynamics that may underlie the conflict. The footing can get rocky for the physician pulled in to resolve what is actually a family conflict about whether to stop active treatment or disconnect a patient from a ventilator.

When an end-of-life conflict appears to defy resolution, medical ethicists recommend using the ultimately practical “four-boxes” approach proposed in the book *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (McGraw-Hill, 2002). That paradigm (see sidebar on page 35) is designed to help physicians identify, analyze, and resolve ethical problems they encounter by effectively breaking down the situation into four components: medical indications, patient preferences, quality of life, and contextual features.

When a patient-physician relationship hits rocky terrain, or a family conflict produces a standoff about treatment, physicians facing ethically difficult situations sometimes fail to avail themselves of the resources that might help. Susan Tolle, MD, director of the Center for Ethics in Health Care at Oregon Health & Science University in Portland, urges physicians to work through advance-care planning with their mentally competent patients as early as possible, preferably before the family enters the scene.

“That’s really what I call preventive ethics, because when the crisis comes, the family usually isn’t ready,” says Dr. Tolle.

Oregon’s pioneering Physician Orders for Life-Sustaining Treatment (POLST) program enables patients and physicians to detail specifically what will and won’t be done, even in the pre-hospital EMS environment, Dr. Tolle explains. The program’s written form, now being adopted by other states, is preferable to the advance directive because POLST constitutes actual medical orders. “If there has been a thoughtful conversation and the patient has participated in that conversation, what a burden is lifted from families,” she says. “There’s a plan, instead of the family member’s receiving the call, ‘Your mom has pneumonia and a temperature of 104. What do you want us to do?’”

Dr. Tolle also advises physicians who are uncomfortable with end-of-life planning—or who see a possible ethical conflict brewing with a patient or family member—to tap outside resources early on. That may be the hospice nurse, medical director, social worker, or the hospital’s ethics committee consultant if there’s a conflict.

Physicians often need help even with advance-planning conversations, she says, “because you have to talk about a lot of hard things, and it can be a difficult conversation to start. There’s this image that only the doctor can talk about these things,” Dr. Tolle says, “but sometimes the doctor isn’t the most skilled in these matters.” Most communities, no matter how small, have someone who can help the physician prepare for or manage a planning conversation or dilemma, she adds, even if only via phone consultation.

One way for physicians to better address end-of-life planning conversations and avoid conflicts is to understand what’s involved in making these choices for themselves, Dr. Emanuel says. “I often ask physicians: ‘Have you filled out the advanced directive and thought about these issues?’” he says. “It’s very important for physicians to experience these things and not just talk about them. Then they can say to their patients, ‘I’ve done it myself, even though I’m still healthy.’ Then you have much more appreciation for the choices and are able to talk about the issues more comfortably.”