FIN
Decisions about medical care often involve complex treatment decisions. As medical technology research advances and treatment options expand, the possibilities in medicine are continually being altered. For clinicians, patients, and family members, medical care’s forward march can translate into new and challenging choices.

Of course, no matter how much the health care system modernizes and evolves, the goal to provide quality patient care will continue to inform health care’s core values. In this sense, medicine will always be an ethical profession, one defined by professional standards and a fundamental responsibility to serve the best interests of patients.

The scope of ethical concerns is unquestionably broad, touching on issues that pervade every aspect of the health care system, including but not limited to the following:

- Advance care planning
- Biomedical technology
- End-of-life care
- Genetics
- Informed consent
- Patient confidentiality
- Patient-provider relationships
- Professional relationships
- Research
- Surrogate decision-making

Because these topics are so diverse, the more inclusive term of bioethics is sometimes used to describe the wide range of ethical concerns in the medical field.
In the U.S., patients have both the legal and ethical right to be involved in the medical care they receive. In turn, providers have an ethical responsibility to help patients take an active role by keeping them informed.10 By supplying the patient with the necessary information, providers pave the way for patients to better participate in decisions related to their health care.

These goals help shape the concept of informed consent, which is defined as “the process by which the treating health care provider discloses appropriate information to a competent patient so that the patient may make a voluntary choice to accept or refuse treatment.”

Informed consent typically covers topics relevant to a decision-making process, according to UW Medicine:

- The nature of the decision or procedure
- Reasonable alternatives to the proposed intervention
- The relevant risks, benefits, and uncertainties related to each alternative
- Assessment of patient understanding
- The acceptance of the intervention by the patient

Despite this more recent focus, the importance of ethics in health care is hardly unique to today’s high-tech system. In fact, medical ethics is a concern with a long history. The American Medical Association (AMA) adopted its Code of Medical Ethics2 (i.e., Code) at its founding convention in 1847.1 In turn, the AMA’s ethical foundations trace their roots back to fifth century B.C. medicine and the writings of the Greek physician Hippocrates and English physician-philosopher Thomas Percival, which provide insights into the goals of medicine as a profession.3 The AMA Code was developed in accordance with the highest mission of the physician community—to relieve the suffering of the ill and always serve the well-being of patients.3

Generally, medical ethics is informed by four principles:

- Autonomy. Every patient has autonomy, or the right to make decisions about the care they receive.
- Beneficence. Health care providers are ethically obligated to always act in the patient’s best interest.
- Nonmaleficence. Ethical medicine adheres to the classic maxim “First do no harm.”
- Justice. In the course of providing patient care, practitioners should consider the just, equitable use of resources within the health care system.

Similarly, the AMA Code delineates several core principles considered essential to the practice of medicine.5 These include ethical obligations such as the duty to provide competent medical care, uphold professional standards, and treat patients with dignity, compassion, and respect for their rights.5 Furthermore, there is an ethical obligation to “safeguard patient confidences and privacy,” as well as to conduct all professional interactions honestly and report unethical or illegal behavior within the profession.5

Additionally, the AMA Code addresses physicians’ responsibility to pursue ongoing medical education, support access to medical care for all people, and participate in activities that improve their communities and enhance public health.5 The standards of conduct that shape the AMA Code also grant physicians the ethical right to choose whom and where they serve, except in emergencies.5

In a physician-led health care system, the AMA Code naturally influences the larger health system culture. But the relevance of any professional or organizational code of medical ethics is contingent upon a code’s ability to reflect and respond to the demands of an evolving medical system. In this sense, codes of medical ethics might best be considered as living, adaptable guides.6

The idea of medical ethics as both dynamic and foundational to the health care system is well understood by experts. “Medical ethics, or bioethics, has always been extremely important,” says Georgina Morley, PhD, MSc, a nursing ethics fellow at the Center for Bioethics at Cleveland Clinic in Ohio. “Obviously, physicians and health care professionals are in positions of great responsibility and privilege, and so we need to ensure that the way they practice is held to the highest ethical standards. Today, it’s even more important because of the advancements in medical technology, which are creating these subliminal spaces between life and death and posing new and different ethical issues every single day for clinicians.”

Consult the guide
In addition to a growing emphasis on end-of-life care, medicine has moved away from the paternalistic physician-patient model toward relationships that instead emphasize patient choice and shared decision-making. This cultural shift in medicine since the 1960s has likely raised the value of ethical decision-making as a deliberative process, one in which specialized expertise in medical ethics assumes a more prominent role.
Consequently, many resources now exist to help physicians and other clinicians address ethical concerns that arise related to patient care. These include the use of trained medical ethicists, university- and hospital-based committees or departments of bioethics, and other resources.

Another way ethical issues are clarified is through an ethics consultation (or ethics work-up). An ethics consultation provides professional assistance to clinicians, patients, and families who request help with any ethical concerns they may have related to patient care. As such, a consultation may be requested to help the involved parties:

- Define their values
- Resolve differing perspectives
- Answer questions related to potential treatment decisions

In a sense, an ethics consultation is about shining a light on assumptions about beliefs or values that may not be fully articulated by the involved parties.

“Our work in medical ethics is about trying to address issues of value that arise in the context of providing health care to patients,” says Denise Dudzinski, PhD, MTS, professor and chair of the bioethics and humanities department at the University of Washington School of Medicine in Seattle. “Oftentimes, core values that we hold become invisible to us over time … because they’re just [a part of] who we are. … Medical ethics try to address issues that are recognized by clinicians as challenging and involving an ethical dimension. We also try to understand the underlying values that are at play in the cultures of medicine and how [these values] interface with other cultures.”

How does an ethics consultation work? At UW Medicine, the University of Washington–affiliated health system serving Seattle and its outlying region, an ethics consultant is always on call. “Clinical staff, patients, and families can [contact] the ethics consultant at any time,” reports Dr. Dudzinski. “The consultant will then confer with the staff to get some initial details about the patient’s case, read the chart, and learn more about what issues are involved. The consultant also speaks to the patient or participates in a family meeting to get a sense of what their values are and what they think is the best course to take. [The consultant] may also speak to members of the ethics committee and confer with other health care providers or clinicians in other specialties. At times, the consultant may also arrange for a multidisciplinary meeting where everyone can talk in more depth, addressing where there may be differences of opinion or values issues that have arisen.”

At the conclusion of this consultative process, the ethics consultant will offer an advisory recommendation. “These recommendations are not clinical recommendations,” explains Dr. Dudzinski. “For example, if the issue that prompted the call for an ethics consultation involved whether to continue ventilator support for a patient with progressive lung disease who is actively dying, an ethics consultant would not write, ‘Withdraw the ventilator’ or ‘Continue the ventilator.’ But we would provide other kinds of guidance that are often process-based and values-based. For example, we would share, based on the discussion that we had with multiple providers, how we would characterize some of the arguments in favor of continuing ventilation and how we would characterize arguments against continuing ventilation.”

In this way, the intent is to establish some common ground or agreement about how to proceed with the patient’s treatment, says Dr. Dudzinski. “What we’re often trying to do is come to a consensus, to find the way—if at all possible—that we can honor the most important values of all parties. Thus, the note [on an ethics consultant’s chart for the patient] would often reflect whatever consensus was reached. For example, it might state, ‘We recommend a palliative care consult-ation,’ or ‘We recommend this kind of communication with the family,’ or ‘We recommend following these provisions in a policy in this way,’ and so on.”

Pathfinding
Like UW Medicine, the Center for Bioethics at Cleveland Clinic is one of the larger programs of its kind. As such, the center’s ethics consultation service is a busy, well-integrated component of the Cleveland Clinic system, especially in the intensive care unit, reports Dr. Molloy. Their staff includes several full-time ethicists, plus fellows who support the consultation process.

“The most common issue for us is [the] withdrawal of life-sustaining treatments: whether or not we’re getting to the end of the road for a patient and whether treatments are now reaching that point of being

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**SOS signals**

Ethics consultations provide aid at critical moments, but how do patients, family members, and health care professionals know when to seek out these services? The Cleveland Clinic outlines several situations in which an ethics consultation would be appropriate:

- Efforts by patient, family, and health care providers to resolve an ethical issue have reached an impasse.
- Decisions need to be made about life-sustaining treatment for a patient who lacks decision-making capacity and for whom an appropriate surrogate [decision-maker] cannot be found.
- A patient’s surrogate [decision-maker] is unable or unwilling to provide a substituted judgment as to what the patient would have wanted.
- Health care professionals wish to discuss ethically supportable strategies that could help prevent an “ethics crisis.”
- The case is ethically challenging, unusual, unprecedented, or complex.”
Hidden treasure

To provide quality health care, accurate diagnoses, and informed recommendations, health care providers must have access to patients’ health records and information. However, this sensitive information can cause harm if shared with others.

Thus, confidentiality acts as a cornerstone for relationships between patients and providers. The expectation of confidentiality derives from the public oath that the physician has taken and from the accepted code of professional ethics, writes Mary Jo Ludwig, MD, and Wylie Burke, MD, PhD. “The physician’s duty to maintain confidentiality extends from respect for the patient’s autonomy.”

The pathway to patient empowerment is often less about determining right from wrong and more focused on how to sort through multiple valid treatment options. An ethics consultation is a considered and collaborative process in which each potential path is carefully thought through before a decision is made to follow a particular treatment.

Bumpy roads

As an ethics consultant, Dr. Dudzinski describes how she typically approaches a consultation request. “[I] run through what I’m hearing about people’s beliefs, what they think is best, their goals, and so on. I do this through a variety of different moral theories I have learned. For example, I think about people’s obligations and rights, what virtues they’re trying to enact and embody, and how these may come into conflict. I think about the harms and the benefits of various courses of action but in terms of moral harms and benefits. I try to ask questions that elicit a deeper understanding.”

If there is disagreement among members of the clinical staff, Dr. Dudzinski endeavors to help each person better understand where the other is coming from. “I try to help name the values that the individuals are holding tightly and don’t want to give up,” she says. “I do this in such a way so that we may now see where there is some common ground.”

Notably, ethics consultations are not designed to address issues of legal misconduct. “I think sometimes people worry that medical ethics [consultants are] the police,” says Dr. Dudzinski. “We’re not the police. Actually, if there’s a case of true misconduct, we’re not involved. You don’t need an ethicist in such circumstances. We are involved in cases where competent, caring, and reasonable people disagree. These are typically more nuanced cases, where we take for granted that everybody is trying to be a good person and has the best interest of the patient in mind. That’s actually our starting point.”

Traversing technology

In recent years, electronic health records (EHRs) have made many improvements to patient care possible:

- More accurate, up-to-date patient health information
- Improved communication among providers
- Safer prescribing
- Reduced paperwork

Yet the use of EHRs poses new, potential ethical and legal concerns. One significant technology-related concern involves protecting the confidentiality of patient health data.

Under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), health care providers are required to have policies in place to protect the privacy of protected health information, in whatever form it may take (e.g., hard copy and electronic). As a part of this act, providers are prohibited from disclosing personal health information without the patient’s authorization. Unfortunately, the electronic transfer of patient data challenges this promised confidentiality.
“[When work] was conducted [with] pen and paper, there were certainly ethical considerations, but it’s become even more challenging now that patient data is moving electronically,” says Robert M. Tennant, MA, director of health information technology policy for the Medical Group Management Association in Washington, D.C. “We’ve got issues of what [patient data] should be released, when [it] should be released, and in what format it should be released. What’s in the best interest of the patient? What could be harmful to the patient? And what is required by the government? Today, we’ve got all of these potentially conflicting issues facing medical practices.”

Concerns about the privacy of patient data may arise with new rules, notes Tennant. The Office of the National Coordinator for Health Information Technology proposed a regulation in early 2019 that would require medical practices to release patient information to third-party software apps at the patient’s request. Currently, the majority of health care apps do not fall under the HIPAA rule, which means that responsibility for protecting patient privacy rests on the shoulders of patients and providers alone.

“The question—and it’s an ethical one—is what’s going to happen to that data once it leaves a medical practice,” says Tennant. “Is there an ethical duty on the part of the practice [and] the physician to counsel the patient before that information is sent?”

To illustrate the potential complexities this issue creates, Tennant describes an example from everyday life. “If someone has a smartphone and has downloaded apps to the phone, how often do they read the terms and conditions before they hit ‘I accept’?” he asks. “For most people, the answer is probably never. Now, what if a large employer requests or requires their employees to use the company’s wellness app? In doing so, [the employees are] then required to have their personal information downloaded. The company could potentially use that information. There could be information there about substance abuse treatment, mental health services, pregnancy, or cancer—information they could use in employment decisions. If employees don’t read the terms and conditions, they’re potentially giving the employer full access to this information.”

Tennant acknowledges this example is perhaps a worst-case scenario but cautions there are other, more common privacy pitfalls associated with electronic data transfers: “A more realistic scenario is that third-party apps will bury in the terms and conditions something along the lines of ‘We reserve the right to sell any of this data.’ So now the flow of data involves an ethical challenge, … because the physician and the practice want the patient to have access to the data. They want the patient to be able to transport that data [and] move it from care setting to care setting. But now there is a concern about the security and privacy of this information. That’s a narrow issue, perhaps, but it’s an important one.”

In response, the Medical Group Management Association and other industry groups are urging government action on the issue, Tennant reports. Some ideas have already been proposed:

- Implementing an accreditation requirement for third-party apps
- Requiring transparency to benefit informed consent for patients
- Encouraging medical practices to offer a handout to patients with a statement of rights or questions to consider about the use of their personal information by third-party apps

“The goal should be to improve protections for patient data, not to restrict the data flow or engage in data blocking, which is illegal according to [the Office of the National Coordinator for Health Information Technology],” explains Tennant. “Our hope is that medical practices will develop a communications strategy to deal with these patient issues. The idea is for practices to really act as an advocate for their patients.”

Know the ropes

Regarding patient confidentiality, Tennant makes an important observation about the difference between ethical versus legal obligations. “The U.S. Office for Civil Rights has basically said that as soon as patient data leaves the practice, the practice no longer has any legal responsibility,” he notes. “That’s fine, but there is still an ethical responsibility. If you, as a provider, know or [are] worried that some type of harm could come to your patient due to the disclosure of patient data, I believe you have an ethical responsibility to let the patient know. Again, you may not be legally bound, but there is a difference between legally bound and ethically bound.”

Tennant offers an instructive example to illustrate his point. “Under HIPAA, a patient can request a hard copy of their medical record,” he says. “Now, under the law, the practice has a right to charge what’s called a reasonable, cost-based fee for this service. In most cases, there is a state-mandated maximum charge that’s usually in the neighborhood of a dollar per page. But a medical record could be two or three hundred pages long. Is the practice going to copy the record and charge the patient $300? Well, that’s not right. So, there are a couple of options. We recommend to our members that they provide this service at no charge. Yes, they are permitted to charge, but we think it’s in the best interest of both parties not to charge for a reasonable request.”

In this instance, Tennant concludes, the ethical obligation of the provider may go beyond the strict provisions of the law.

All aboard

Ethical decisions in medicine are not just about the most complex or difficult decisions. “We often think about the really big ethical issues, like the classic issues...
of ending treatment or moral conflicts between families and clinicians,” observes Dr. Morley. “But ethics pervades everything that we do. It’s also about whether you are kind to somebody [and] whether you treat them with dignity. In [every aspect of health care], there is some sort of ethical implication. I try to think about ethics in this way, rather than always about the grand moral dilemmas.”

“I believe creating an ethical climate requires everybody in an organization to be committed—for there to be a clear vision of what the ethical climate looks like from leadership and then for everyone in the organization to be committed to ensuring they have that ethical climate,” concludes Dr. Morley.

Of course, as health care professionals, medical assistants are expected to adhere to ethical practices in their work, both with patients and colleagues. Accordingly, the Code of Ethics developed by the American Association of Medical Assistants® (AAMA) addresses several ethical responsibilities applicable to the profession:

- Respect the dignity of patients
- Protect patient confidentiality under the law
- Demonstrate a commitment to ongoing professional education
- Participate in service activities to improve the health and well-being of their communities

“An important aspect of health care’s ethical mission is to always serve the patient’s best interests, which includes the responsibility to always treat patients in a respectful manner,” observes Deborah Siclari, CMA (AAMA), practice manager for Pediatric Ophthalmology of New Jersey in Wayne, New Jersey. “We want our staff to handle front-desk responsibilities in a professional way. These responsibilities include a variety of tasks, such as explaining new or unfamiliar financial policies to the parents of our pediatric patients, asking for updated insurance information, requesting signed authorizations for the release of patient information, and so on. At times, a parent or guardian may not understand why such requests are necessary. Or they might be unhappy when we explain how vision and medical insurance differ in ophthalmology and why a procedure may not be covered by their insurer. I always emphasize to our staff that we’re there to serve the patient’s needs, and this includes being calm and courteous even when the [patient or patient’s family] is not. Part of our ethical obligation [is] to stay professional even when someone is upset or disrespectful.”

Such advice extends to how staff work with one another, adds Siclari. “When patients come to the office and see a team working together [and] treating each other with respect, they feel as though they’re in the right place and that we’re there to help them. I do think patients pick up on these things in the office. We need to be there for each other. That, to me, is the best thing that we can do for patients. It’s definitely part of our ethical obligations as professionals.”

From the clinical examination room to the office administration, ethical obligations inform the work of every member of the health care team. Therefore, the mission of health care entails more than expertise in science-based medicine, technical knowledge, or familiarity with insurance rules. In the end, the many challenges involved in providing quality patient care are also built on the honor, integrity, and professionalism of health care professionals, whose commitment to ethical standards and practices helps to ensure the core integrity of the health care system.

References