

# Clinical Ethics and Patient Advocacy

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Clinical ethics is a practical discipline that seeks reasonable resolution of value-based conflict and uncertainty in patient care.<sup>1</sup> *Practical* implies a focus on specific, manageable problems and identifying and pursuing what's workable. This means avoiding useless distractions such as going off on a tangent that no problem can be fixed until all the chronic problems in the American health care system are resolved. Reasonable resolution rules out reliance on categorical absolutes, such as "the hospital is always right," "the doctor is always right," "the nurse is always right," "the patient (or family) is always right," or "the law is always right." Hospital administrators disagree with each other. Policies and consensus statements require interpretation. Doctors disagree about what should be done, as do nurses and other providers. Family members disagree with each other and with their sick or injured loved one about plans of care. Statutes and case law vary by jurisdiction. Lawyers and judges disagree about what authority should control their arguments and interpretations. Sometimes one or another of these seems mostly right, but usually not categorically. Uncertainty and conflict impose delay, an enemy of timely decision-making in patient care. The challenge for practitioners of clinical ethics is to help find a reasonable way through these difficulties. Reasonable resolution affirmatively presupposes:

- Having good clinical information.
- Understanding the answers to questions such as: What is the patient's diagnosis and current condition? What is his prognosis for recovery to his pre-morbid state or for survival? What are the goals of care? With what probability will the current plan of care achieve them? How long will it take to judge the plan a success or failure? If the care plan fails, should the goals of care be modified? If so, what options are available for pursuing them?
- Impartially taking into account the rights and responsibilities of those involved in a conflict as customarily understood.

- Promoting candid communication and trust between decision-making partners.
- Working in good faith and in a spirit of compromise.

Customary understandings of patients' rights and care providers' responsibilities necessarily are imperfect, and sometimes contradictory, but they roughly circumscribe the range of options among which reasonable ones must be found. The medical, surgical, and nursing professions have promulgated ethical opinions on a broad range of practice issues, many of which are readily available on the internet. The hospital has long been a venue for providing in-patient care, and all hospitals have policies to guide relations

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between it and the professionals who provide services to patients. Federal and state statutes and case law provide additional standards that must be considered. All of these are normative resources when addressing apparently novel conflicts. The practitioner of clinical ethics cannot make useful suggestions for resolving conflict and uncertainty in ignorance of these judgment-guiding resources.

An innovation in organ procurement protocols for donation after cardiac death (DCD), which are now mandatory for medical centers that perform transplants, has garnered attention from practitioners of clinical ethics. These protocols provide for controlled withdrawal of mechanical ventilation from properly consented organ donors whose heart stops beating in the operating room. They also provide for using opioid medications to treat the dying donor's apparent distress. The protocols anticipate that the properly-selected donors will die

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from cardiac arrest within a predictable timeframe, normally within 90 minutes from withdrawal of the ventilator and extubation. And, of course, it is further provided that resuscitation shall not be attempted when cardiac arrest occurs.

For operating room personnel unaccustomed to a planned provocation of cardiac arrest and a passive response to it, this innovation in organ procurement caused considerable discomfort. Because of the vigilance of anesthesiologists and surgeons, intraoperative deaths have been dramatically reduced. In effect, patients are monitored and resuscitated continuously while in the operating room. Cardiac arrest is treated reflexively and aggressively.<sup>2-4</sup> The idea of standing by during an arrest, of not treating it, is outside the experience of operating room personnel. To some, the DCD protocol seemed indistinguishable from active euthanasia, and they have voiced their strong objections.<sup>5</sup> Yet customary understandings of patient rights in the United States include the right to forgo CPR, to have life-sustaining treatment discontinued, the right to receive medication sufficient to forestall associated distress, and the right to donate organs after death. Our pluralistic society also includes a customary understanding that health care workers should not to be compelled to participate in procedures to which they object on ethical grounds.

Practitioners of clinical ethics have addressed this value-based conflict with in-service education to review current understandings of patient rights and surrogate decision-making at the end of life. Practitioners of palliative medicine who regularly provide comfort care for dying patients have provided a practical perspective regarding how opioids are managed in such circumstances. This educational exercise put objecting operating room personnel in a better position to consider whether their discomfort with the new protocol resulted from unfamiliarity with DCD procedures or from more profound ethical considerations.

To avoid offensive coercing of those with lingering doubts, assurance is given that they will not be compelled to participate in activities to which they have abiding objections. Some are reassured, but not all. Schedule adjustments and transfers allow respect for sturdy dissenters. Whether their unrelieved discomfort is genuinely ethical is not further explored. Relieving providers' mental distress is important. Patients and the hospital have an interest that the service of operating room personnel not be grudging.

Resolution of value-based conflict is rarely perfect or exclusively correct. *Reasonable* implies that "best" and "better" must not be adversaries of "acceptable" and "good enough." For the question of whether DCD is really euthanasia or not, clinical ethics defers to the disciplines of bioethics, theology, and philosophy.

## The Scope of Clinical Ethics

Clinical ethics finds practical application in three characteristic activities:

- Advising hospital administration or medical staff on patient rights policies. For example:

- Whether and how to recognize the validity of so-called "portable no-CPR orders" when signed by physicians not on the hospital's medical staff or by practitioners whose privileges would not have included writing Do Not Resuscitate (DNR) orders, even if on staff.
  - Whether a patient's hospital DNR should be automatically suspended in the perioperative period (for a palliative operation).
  - Crafting a fair procedure on how to respond to patient (or family) demands for specific treatments the attending physician has not offered and refuses to offer.
  - How to discharge the obligation to disclose errors both when harm results and when it does not.
- Educating the hospital's health care professionals about their ethical obligations in patient care under public policies such as the Patient Self-Determination Act (PSDA), the Emergency Treatment and Active Labor Act (EMTALA), the Health Insurance Portability and Accountability Act (HIPAA), and North Carolina's Natural Death Act (NDA). For example:
    - Whether physicians who have properly discharged patients from their outpatient practices for outrageous, disruptive, or even violent behavior should nevertheless take care of those very same patients when summoned to the hospital, in an on-call capacity, by an emergency physician.
    - What confidential health information should be shared with a surrogate to enable informed consent discussions on the patient's behalf.
    - How a physician should determine whether a patient's condition is terminal and incurable, what qualifies as extraordinary means, or whether living wills executed outside the state should be respected.
  - Consulting on cases involving conflict over the care of individual patients. For example:
    - Should an indwelling implantable cardiac defibrillator (ICD) be disabled at the request of a terminally ill patient when the physician believes, to a high degree of medical certainty, that a lethal arrhythmia will occur as a result but recognizes that a functioning ICD will interfere with the patient's no-CPR order?
    - Should a physician allow a patient-designated surrogate decision-maker to reverse the patient's specific, documented prior choices regarding no CPR and no non-oral nutritional support?
    - May a well-informed patient demand amputation of a traumatically injured limb despite his surgeon's belief that it is unethical to amputate a limb he has determined to be salvageable albeit one with impaired function?

- Does equality of basic health care rights imply that a never-competent patient has the same right (exercised on her behalf by a surrogate) as a competent patient to refuse a feeding tube?
- Does a pregnant adult trauma victim have the right to jeopardize her 20-week old fetus's life as well as her own life by refusing a blood transfusion on religious grounds?
- Is it unethical for a physician to perform an elective caesarean section at a patient's request when the surgeon agrees that the patient has reasonably determined that the risks of vaginal delivery vs. C-section delivery in her own case are roughly equal? Does respecting patient self-determination mean that the patient should get to choose C-section despite the fact there are no medical indications for it?

## Ethics Committees

Clinical ethics has been a focus of discussion since *In re Quinlan* (1976)<sup>6</sup> when the New Jersey Supreme Court endorsed the idea that value-based disputes over a patient's care that arise in the hospital (i.e., whether or not it is permissible to honor a guardian's request to withdraw a ventilator from a patient who is non-terminal but in a persistent vegetative state) should be addressed within the hospital by an interdisciplinary consultative process (an ethics committee) rather than in a court of law.

At the time of the *Quinlan* decision, few hospitals had ethics committees. Clinical ethics was an informal discipline, variously practiced on an *ad hoc*, part-time basis by hospital chaplains, social workers, hospital legal counsel, risk managers, nurse managers, medical directors of intensive care units, and medical executive committee members. These health care professionals probably did not think of themselves as practitioners of clinical ethics. Nor were they listed in the hospital directory under "ethics." Rather, they had acquired personal reputations as the "go to" people to reliably, but most of all quietly, resolve value-based uncertainty and conflict in the hospital. In other words, *valued-based uncertainty and conflict over patient care in the hospital creates an informal market for ethics advice*. Every hospital has long had one or more providers of the service, irrespective that the service has not been dubbed "clinical ethics" nor its practitioners designated as "clinical ethicists."

Ethics committees (usually organized with subcommittees for policy, education, and consultation) have rapidly proliferated since *Quinlan*. Some states require hospitals to have them by statute (e.g., Maryland and Hawaii). The Joint Commission on Accreditation of Healthcare Organizations, by demanding a mechanism for addressing value-based conflicts in patient care that arise within the institution, effectively requires hospitals to have an ethics committee or an ethics consultation service. Today, virtually all hospitals and many long-term care facilities have ethics committees of some kind.

By establishing an ethics committee, a hospital openly acknowledges the possibility of having in-house value-based conflicts over patient care. However challenges exist in implementing effective ethics committees. Indeed, ethics committees in most hospitals meet infrequently and rarely get consulted. It is not unusual for a newly established ethics committee to meet monthly at first, then quarterly over the ensuing years, then semiannually, and then only on an as-needed basis. Securing physicians' commitment to take an active role in the ethics committee's work has proven very difficult. A recent study found that ethics committees average only three consults per year.<sup>7</sup>

Additionally, individuals (such as legal counsel or a risk manager) and other hospital committees (such as nursing quality assurance) who have been practicing clinical ethics (functionally, if not in name) long before an ethics committee was established in the hospital have not always welcomed an untested, unknown competitor with open arms. Indeed, they retain and often continue to exercise their power to short stop value-based conflicts before they ever reach the ethics committee.

## Clinical Ethics and Ethics Consultation

When ethics committees were first getting established, each of the three practical applications of clinical ethics mentioned above (policy, education, and case consultation) was practiced by committee. However, because regular committee meetings rarely occur more often than once a month and because assembling the entire committee quickly, on an *ad hoc* basis, is difficult and deters the seeking of timely consultation, case consultation has increasingly devolved to clinical ethicists who serve on the committee's ethics consultation service.

Clinical ethic consultants are expected to timely respond to consultation requests. They commonly carry pagers and have on-call responsibilities. When consulted on a case these individuals typically:

- Discuss the patient's case with the attending physician, consulting physicians, nurses, the patient (if he or she is able), and family members;
- Review the patient's medical record;
- Organize patient care conferences; and
- Write entries in the progress notes documenting their ethical assessments and recommendations.

Members of the ethics consult service are drawn from a variety of professional backgrounds including medicine, surgery, nursing, social work, pastoral care, law, hospital administration, psychiatry, psychology, and academic philosophy. Thus the ethics consultant faces a challenge: to take advantage of his or her professional knowledge and training but avoid biasing the resolution of a value-based conflict by a procrustean reduction to a medical, surgical, spiritual, legal, psychiatric, or philosophical problem.

## Medical/Surgical Consultation and Ethics Consultation

When physicians or surgeons initially apply for hospital privileges (and periodically thereafter), they must submit their credentials (medical degree, certification of residency, state medical license, fellowship, ABMS certification, work record of previous service) for review by medical staff, agree to a national practitioner database query, and undergo a criminal background check, all in support of a request for a delineation of privileges (DOP). The hospital credentials committee is responsible (and liable) for exercising due care in determining that every individual who operates under its authority in the hospital has sufficient knowledge, training, and skill to safely perform the services specified in his or her DOP. This due diligence is not equally applied to ethics committee members who perform consults in the hospital.

Despite the fact that the medical staff bylaws define the ethics committee's membership, functions, and services, the credentials committee typically does not evaluate the professional training and experience of individuals privileged to provide ethics consultation in the hospital. For example, suppose a medical doctor or surgeon member of the medical staff has been appointed to the ethics committee with a 0.5 FTE for service as an ethics consultant. Medical staff membership implies that he or she already has a DOP that may include, for example, colonoscopy, central venous catheter placement, hemodialysis, or placement of drug-eluting stents in the coronary arteries. Ethics consultation has been defined as "...the provision of *specialized help* in identifying, analyzing, and resolving ethical problems that arise in clinical care."<sup>8</sup> Assume that a hypothetical DOP for clinical ethics consultation would specify as privileges the activities mentioned above (to interview a patient's attending physician and nurses; to review all relevant aspects of a patient's chart, including other consultants' notes; and to write progress notes in the chart that include an ethical analysis of the value-based conflict presented by the case, together with recommendations for next steps or a reasonable resolution).

What education, training, and skill should be demanded in support of a DOP for reasonably resolving value-based conflicts and uncertainties in patient care? Having sufficient education, training, and skill to secure a DOP that includes colonoscopy would not necessarily be found sufficient for a DOP that includes laparoscopic hernia repair. Similarly, having sufficient education, training, and skill for either of those privileges would not necessarily support a DOP for ethics consultation. Comparatively few physicians have had a course in medical ethics. Fewer still have had any training in conflict resolution. Now, suppose the would-be ethics consultant is a cleric, nurse, social worker, lawyer, or philosopher. Wouldn't it seem reasonable that the credentials committee should evaluate his or her terminal degree, certifications, if any, graduate level course work in ethics, and references testifying to the applicant's probity, impartiality, and good judgment before approving a DOP for ethics consultation? This does not happen today.

## Clinical Ethics and Patient Advocacy

Any person who is sick enough to warrant hospital admission is not at his best, not capable of jealously looking out for and defending the interests that his illness puts at risk. Well-known health care lawyer George Annas argues that every hospitalized patient needs a personal advocate.<sup>9</sup> The advocate Annas has in mind is a vigilant individual, ideally at the bedside 24-hours-a-day. He continuously monitors the patient's condition for any worrisome change and speaks up promptly, aggressively, and insistently to alert hospital staff. To prevent injury from errors, the advocates scrutinizes and records the name of every care provider and every intervention directed at the patient, challenging any that don't make sense.

Advocacy presupposes adversity.<sup>10</sup> If so, patient advocates must have adversaries. And in Annas's scheme of things, the hospital and all those who work in it should be regarded not simply as caregivers but also as potential patient adversaries. Their work burden, momentary attention lapses, and the general human tendency to rely on a routine instead of investigating every irregularity may all imperil the patient.

Annas summarily dismisses the suggestion that everyone in the hospital and especially its nurses and doctors are patient advocates. They are not, nor can they be. Their loyalties are divided among other patients; duties to partners, colleagues, and managed care plans; documentation duties; hospital politics; and other concerns. But if doctors and nurses cannot be patient advocates, neither can practitioners of clinical ethics — not in Annas's sense. Nor should they try.

Patients have rights. The clinical ethicist must see that these rights are known and respected — within a framework of customary understandings that includes due respect for provider responsibilities, including upholding applicable institutional rules. Patient rights have limits. Annas's patient advocate is not inherently concerned about those, nor is he necessarily reasonable in asserting the patient's rights. Instead, the advocate aggressively speaks up for and pushes the interests of the patient against all resistance posed by adversaries. Such vigorous advocacy poses a risk—needlessly proliferating adversaries. The ideal patient advocate relents only when further aggressive assertion risks making the patient worse off, at the limit when no one remains a willing provider of service.

## Criticism of Clinical Ethics

Some critics doubt that there is such a thing as expertise in clinical ethics.<sup>11</sup> They wonder what teachable professional competence would underwrite a clinical skill in reasonably resolving value-based conflicts in patient care. What scholarly methodology would enable its experts reliably to generate solutions to such problems?

This challenge expresses a version of methodological skepticism. The argument is that claims of moral knowledge and ethical expertise necessarily presuppose a logically coherent methodology, mastery of which enables an expert to

derive moral truths and univocal resolution of value-based conflicts and uncertainties. But, manifestly, no such method exists. Therefore the clinical ethicist's pretensions to have moral knowledge and/or ethical expertise are unfounded.

The major premise of this criticism is false. No discipline has such a methodology—not the natural sciences, not mathematics, and not the social sciences. More than 2,300 years ago, Aristotle warned that in ethics we must not demand greater precision and rigor than the subject matter admits. And indeed, in ethics we are stuck with vague concepts such as “appropriate/inappropriate,” and conflicting principles such as patient autonomy/patient-centered-paternalism that fuel persistent disagreements about the scope of patient rights and the limits of fiduciary responsibility. Nevertheless we are able to separate ill-considered opinions from those that are well-grounded in those customary understandings that enable rational discussion of what should be done.

Critics of professionalizing clinical ethics point to an apparent irony—clinical ethics consultants lack a code of ethics with a provision declaring where their professional loyalty lies. Ethics consultants have a conflict of interest by virtue of being on the hospital's medical staff or being its employee. Or might not the ethics consult's commitment to certain religious beliefs (or his lack of commitment to any such beliefs) or his political or cultural beliefs color his judgment? If so, shouldn't the ethics consultant declare all known sources of bias that apply to him so that others may discount his bona fides at a rate that seems good to them? A code of ethics would make public what interests the ethics consultant serves and what interests should trump in conflicts. Finally, might not a hospital's having an ethics consultation service create a moral hazard by encouraging its clinicians to delegate their problems to the ethics consultant rather than shoulder the responsibility themselves? Each of these criticisms has merit, but of different kinds.

Hospitals and their medical staffs should ensure that individuals on the ethics consult service are competent and can be trusted with their privileges. Currently, there is no customary understanding regarding how this should be done. Is it alarming the clinical ethicists lack a code of ethics? That

depends on whether one suspects that, but for a code of ethics, ethics consultants are at liberty to engage in rogue behavior, violate patients' rights, and put at risk the interests of everyone in the hospital. “Loose cannons” have a short shelf life, and appropriately so.

Recommendations from an ethics committee or consultant are simply that: recommendations. Their actionable merit, if any, will be a function of their reasonableness as perceived by professionals who have the responsibility of deciding whether to accept them when deciding what to do. Clinical ethics, as defined in this article, is a discipline of very long-standing, albeit informal as a practice. It pre-dates ethic committees and their consultation services. The fact that most ethics committees are rarely consulted, on average getting three consults per year,<sup>7</sup> suggests that most value-based conflicts in patient care are managed outside of the ethics committee or its consult service. Codes of ethics or certification for ethics consultants will not necessarily attract more business.

Conflicts of interest are problematic but also as numerous as the incentives presented by a particular situation; the motivational tendency of each is variable. Will an ethics consultant automatically bias his or her judgment toward the interests of whoever pays him? If so, does that mean paying attention to interests independent from those of effectively performing his assigned duties? Indeed, there is no reason to suppose that an ethics consultant would have any special insight into the larger interests of the medical staff, the nursing staff, or the hospital or that it would be somehow advantageous for him to pursue those interests rather than the tasks alluded to above.

I have argued that clinical ethics is a practical discipline. It is not new. Its practitioners, providers of ethics advice, have long been on service in the hospital. By contrast, having individuals in the hospital who self-identify as “clinical ethicists” is comparatively new. These newcomers have not yet achieved widespread success in wresting the practice from their much better established competitors. Nor will they succeed until and unless they are perceived by the community they seek to serve as providing a truly valuable service, at least marginally better than those they (unknowingly) compete with. **NCMJ**

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