CHEST Medical Ethics

The Law and Its Interaction With Medical Ethics in End-of-Life Decision Making

Kathy L. Cerminara, JD, LLM, JSD

The previous two articles in this series explored the historical and theoretical development of medical decision making from initial reliance on medical beneficence to a more recent emphasis on patient autonomy. The law of withholding and withdrawal of treatment has much in common with medical ethics. It is based on concerns about patient autonomy expressed by courts, legislatures, and the executive branch of the government. Legally, the patient's right of self-determination has been based on a variety of sources ranging from state and federal constitutions to the common law of torts and from cases to statutes and regulations. Understanding the various sources of the law, the distinctions among those sources, and the interaction of the branches of government in this context assists in understanding the law itself. In our federalist system of government, significant legal variations can exist among the states, but although technically valid, excessive concern about compliance with the precise contours of each state's statute when surrogate decision makers are engaging in bedside deliberations is unnecessary. Regardless of source or precise legal contours, the overall goal, which neither the physician nor the patient's surrogate or proxy decision makers should forget, is to honor what the patient would want to have done. Physicians and attorneys will agree on that as a matter of both ethics and the law.

CHEST 2011; 140(3):775–780

Editor's note: *This essay is the third article in the Law and Medicine curriculum of the ongoing "Medical Ethics" series. To view all articles from the core curriculum, visit http://chestjournal.chestpubs.org/cgi/collection/medethics.*

—Constantine A. Manthous, MD, FCCP, Section, Editor, Medical Ethics

The previous two articles[1,2] in this series explored the historical and theoretical development of medical decision making from initial reliance on medical beneficence to a more recent emphasis on patient autonomy. As noted, "the right of a patient to make decisions at the end of life (for instance via advance directives) is rooted in the concept of the patient's right of self-determination as ethically justified by the principle of respecting patient autonomy."[2] Legally, the patient's right of self-determination has been based on a variety of sources ranging from constitutions to common law and from cases to statutes and regulations. Understanding the various sources of the law and the distinctions among those sources assists in understanding the law itself. Toward that end, this article explores the sources of the law of end-of-life decision making, the relationship among the branches of government as they relate to that law, and the ways state law has facilitated end-of-life medical decision making.

Sources of the Law of End-of-Life Decision Making

The law of end-of-life decision making may be based on a variety of sources. The first basis, in a state or federal constitution, is broad and reflects an abstract respect for the ability, or liberty, of people to make their own decisions about private matters. Another basis, in tort law, arises from a respect for

---

Manuscript received June 22, 2010; revision accepted June 29, 2011.

Affiliations: From the Shepard Broad Law Center, Nova Southeastern University, Ft Lauderdale, FL.

Correspondence to: Kathy L. Cerminara, JD, LLM, JSD, Shepard Broad Law Center, Nova Southeastern University, 3305 College Ave, Ft Lauderdale, FL 33314; e-mail: cerminarak@nsu.law.nova.edu

DOI: 10.1378/chest.10-1612

the inviolability of a person's control over his or her own body. In addition to constitutional and tort law, statutes and regulations may govern end-of-life decision making.

Determining the basis of the law has both theoretical and practical import. As a matter of theory, both constitutional and tort law are closely connected to the ethical concept of autonomy, yet they differ in important ways. Tort law recognizes the core values of privacy and bodily integrity, but constitutional protections secure them more broadly and strongly. State and federal constitutions establish broad, sweeping rules, whereas tort law exists on a smaller scale, largely to compensate persons for injuries. As a practical matter, state and federal legislatures may alter tort rulings by passing statutes. In contrast, legislatures must obey both state and federal constitutions; any statutes they pass must be constitutional in order to have effect.

The constitutional roots of end-of-life decision-making law are deep. Most legal scholars consider *In re Quinlan*,[3] a constitutional law decision, to be the seminal end-of-life decision-making case. In *Quinlan*, Karen Ann Quinlan, a patient in a persistent vegetative state, was maintained on a respirator because she had stopped breathing for at least two 15-min periods for unknown reasons. When her parents asked her attending physician to disconnect the respirator, he refused "based upon his conception of medical standards, practice and ethics"[3] as they existed at that time in 1975. The New Jersey Supreme Court acknowledged the difficult legal and ethical questions the case presented but then recounted testimony of other physicians that medical practice condoned distinctions in care based on whether patients were terminally ill. Virtually equating Quinlan's vegetative state with terminal illness because both are incurable, the court concluded:

> We glean from the record here that physicians distinguish between curing the ill and comforting and easing the dying; that they refuse to treat the curable as if they were dying or ought to die, and that they have sometimes refused to treat the hopeless and dying as if they were curable. In this sense, . . . many of them have refused to inflict an undesired prolongation of the process of dying on a patient in irreversible condition when it is clear that such 'therapy' offers neither human nor humane benefit. We think these attitudes represent a balanced implementation of a profoundly realistic perspective on the meaning of life and death and that they respect the whole Judeo-Christian tradition of regard for human life. No less would they seem consistent with the moral matrix of medicine, "to heal," very much in the sense of the endless mission of the law, "to do justice."[3]

The *Quinlan* court thus assured physicians that they would not violate medical standards if they complied with the wishes of a patient's guardian in discontinuing respirator support in such circumstances. Legally, the court had "no hesitancy" in ruling that Quinlan herself, if capable of making medical decisions, could require that the respirator be disconnected: "No external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life."[3] Analyzing the case as involving a constitutional right of privacy of "personal decision" under both the US and the New Jersey constitutions, the court ruled that neither the state's interest in preservation of life nor concerns about medical ethics outweighed Quinlan's right to choose to refuse respirator support. Moreover, it ruled that Quinlan had not lost that right through incapacity. Rather, it held that "the only practical way to prevent destruction of the right is to permit the guardian and family to Karen to render their best judgment…as to whether she would exercise it in these circumstances."[3]

The reader should not assume that state and federal constitutions are necessarily duplicative merely because the *Quinlan* court recognized a constitutional right in both the US and the New Jersey constitutions. As a matter of constitutional law, the federal Constitution is a floor, not a ceiling, meaning that states must afford their residents at least the constitutional rights the federal government guarantees and may provide more. Some state constitutions are quite explicit with respect to the privacy rights of their residents. For example, article II of Montana's constitution explicitly addresses two different rights patients often claim in end-of-life decision-making cases, stating both that "the right of human dignity is inviolable"(§4) and that "the right of individual privacy…shall not be infringed without the showing of a compelling state interest" (§10).

Thus far, the US Supreme Court has refused to expressly rule that the federal Constitution guarantees a right to refuse life-sustaining treatment, but the door is open for such a ruling. In the highly publicized case of Nancy Beth Cruzan in 1990, the US Supreme Court refrained from finding such a right, transformed by that time, in legal terms, from a privacy right into a "liberty interest." Instead, it held that "the principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."[4] The Court has since explained that in *Cruzan*, it "assumed, and strongly suggested," that the federal Constitution protects the right to refuse life-sustaining treatment.[5]

JUDICIAL, LEGISLATIVE, AND EXECUTIVE POWERS

Understanding the way the three branches of government interact is just as useful as understanding the sources of the law when considering end-of-life decision-making issues. Just as Quinlan sparked a dispute that led to the seminal end-of-life decision-making case, so did Theresa Marie Schiavo, also a young woman in a persistent vegetative state, spark a dispute that revealed that many citizens and legislators did not understand or willfully disregarded the way the branches of government interact. The *Schiavo* case in the late 1990s and early 2000s captured the attention of the nation particularly because it involved striking showdowns between the judicial branch of government on one side and the legislative and executive branches on the other. Nearly prompting a constitutional crisis, the Florida Legislature, Florida Governor Jeb Bush, the US Congress, and US President George W. Bush attempted repeatedly to intervene in and reverse judicial decisions that authorized the withdrawal of medically supplied nutrition and hydration from Schiavo. It is well established in the law, however, that neither the legislative nor the executive branches of government may retroactively change the result of a judicial decision in a particular case. To permit otherwise would be to eliminate a major "check" the judiciary places on the legislative and executive branches in the US system of constitutional government.[6]

Although courts often have stated that they wish not to interfere with the private, personal area of end-of-life medical decision making unless required to do so, sometimes patients, family members, or health-care providers find it necessary to seek judicial resolution of disputes. If a patient's family, for example, believes that the patient's designated surrogate decision maker is not honoring the patient's wishes, there must be a way to address their concerns. The courts are available to resolve such concerns.

When a court resolves such a case, some citizens may wish, as several did in *Schiavo*, to petition the executive and legislative branches to reverse the effect of decisions made by the judicial branch. Acquiescing to such requests is unwise and inadvisable, however, because the roles of elected officials controlling the legislative and executive branches differ from the roles of officials who are either wholly or partially insulated from election forces, such as those in the judicial branch in many jurisdictions.

The roles of trial and appellate court judges contrast both with each other and with the role of legislatures. Trial court judges are responsible for supervising the parties' introduction of evidence into a record and for rendering initial decisions, sometimes with the assistance of juries. Appellate court judges are responsible for reviewing the legal issues in trial court decisions only, not for redeciding facts. Judges at all levels are responsible only for deciding the precise cases before them, primarily ruling on the legality or illegality of past actions. Legislatures, in contrast to both levels of the judiciary, are responsible for setting forth general rules to guide future conduct. They think broadly and enact laws to govern their citizens from the effective date of their statutes onward, without retroactive effect.

Applying this general construct to the end-of-life decision-making arena assists in understanding the usual areas of responsibility of the three governmental branches. State legislatures have put into place statutes that primarily govern future conduct, most importantly advance directive statutes. Agencies, which are instruments of the executive branch of both state and federal governments, are responsible for administering the laws the legislatures have passed, using rules and regulations to do so. The courts are responsible for deciding cases brought before them when disputes arise.

PATIENT CHOICES TO WITHHOLD OR WITHDRAW LIFE-PROLONGING TREATMENT

There is no need to turn to statutes, regulations, or even likely the courts when an adult patient with decision-making capacity asks a physician to withhold or withdraw life-prolonging treatment. (Separate considerations, not addressed here, govern decision making on behalf of children, who generally are not considered to be legally capable of making such decisions.) Adult patients with capacity who are acting voluntarily may refuse any and all medical treatments as a function of their autonomy in ethical terms and as a function of their rights to control their own bodily integrity in legal terms. The main concerns with these patients are whether they truly have decision-making capacity, that is, whether they understand their medical conditions, their treatment options, and the consequences of their decisions. Medical practitioners are empowered by the law to decide whether a patient has capacity, and capacity is presumed. Although some health-care institutions prefer that specialists, such as psychiatrists, determine whether patients have capacity, there is no such legal requirement in most states. If a patient with capacity is acting voluntarily (without coercion), then as a matter of tort law, it is battery to administer or to continue to administer treatment in the face of the patient's refusal.

Incapacitated Patients: "Voice" Through Statutes, Rules, and Regulations

The cases of patients who have lost decision-making capacity, regardless of whether they have been adjudicated incompetent, present more issues. Before addressing these issues, a discussion about terminology is in order. Some legal and medical practitioners carefully distinguish between the terms *competency* and *capacity*, whereas others use them virtually interchangeably. Both are correct. Some courts have discounted the need to distinguish, expressing an inclination to use the terms interchangeably,[7] whereas risk management specialists feel most comfortable retaining the distinction. *Competence* is the technical legal term that attaches to a judicial determination of whether an individual has the capacity to make the decisions he or she is making, whether about medical treatment, disposition of property through a will, or a contract to deliver a service. An adjudication of incompetency is required before appointment of a guardian, but because appointment of a guardian is a drastic step, some patients who lack medical decision-making capacity may not—and need not—actually be declared incompetent under the law. Conversely, a patient who is competent generally under the law may temporarily lose capacity to make medical decisions. Both competency and capacity inquiries are context specific, meaning that a patient may have capacity to make medical decisions but not to maintain his or her financial affairs (and vice versa).

A patient without decision-making capacity retains the right to refuse treatment, as the *Quinlan* court ruled in 1976, but because that patient cannot speak at the time of the decision, the law has had to devise tools to use in order to determine the patient's wishes. Statutory living wills, surrogate or proxy designations, and the relatively new Physicians Orders for Life-Sustaining Treatment instrument can serve as indications of the patient's wishes, specifying treatment choices; the identity of one or more persons to whom he or she has delegated decision-making authority; or both. Thus, such statutes are instruments for giving voice to incapacitated patients.

Moreover, a patient who has lost decision-making capacity who has not completed an advance directive has not lost his or her right to direct the course of care. Rather, many states have enacted statutes pursuant to which medical professionals can determine who should speak on behalf of the patient in question. To the extent that patients without capacity can display emotion or express opinions, their actions and expressions should be taken into account in determining whether to withhold or to withdraw treatment.

State-by-State Variations in Statutes, Rules, and Regulations

Legislatures in all 50 states and the District of Columbia have passed some form of advance directive statute addressing either patient designations of surrogate decision-makers or patient wishes regarding end-of-life care, if not both.[8] Many state legislatures also have passed statutes that list, by category, persons to whom physicians can turn for medical decision making if an incapacitated patient has not previously designated a decision maker.[9] In addition, state legislatures and administrative agencies relatively recently have begun recognizing Physicians Orders for Life-Sustaining Treatment instrument through statutes and regulations.[10] State-by-state development is necessary because, as matters of health and welfare are subject to state rather than to federal control, there is and likely can be no overarching federal advance directive statute. Because each state is a sovereign entity, the precise contours of the law necessarily will vary state to state.[11] Citizens of Minnesota may not (and likely do not) have the same values and concerns as citizens of Connecticut, and each state's law will and should reflect those differences.

For example, and as will be explored in greater detail in the next article in this series, terminology may vary from state to state. Most states use the term *proxy* to describe a person a patient has designated to make medical decisions on his or her behalf after loss of capacity; others use the term "surrogate" to refer to such a person. The converse also is true: If a state uses the term "proxy" to describe the person a patient has designated, then it must use another term (usually "surrogate") to describe the person to whom a physician can turn under the law to make decisions in the absence of a patient designation. In states in which the term "surrogate" is already in use to describe patient designees, those the law designates as decision-makers are termed "proxies."

In a related vein, determining whether an illness is termed "terminal" or whether a patient is referred to as "terminally ill" is both context specific and state specific. Under Florida's advance directive statutes, the term "terminal condition" refers to "a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death."[12] A physician in Florida considering whether a patient is terminally ill for purposes of Medicare payment for hospice services, however, must abide by federal law, which requires that the patient "has a medical prognosis that his or her life expectancy is six months or less if the illness runs its normal course."[13] The federal definition also will govern certification of a patient as being terminally ill for Medicare hospice purposes if the physician and the patient are in Tennessee, yet Tennessee state law governs that categorization for purposes of determining whether a patient is in a condition in which his or her advance directives apply. The Tennessee advance directive statute, in contrast to Florida's, includes patients in persistent vegetative states among those with terminal conditions.[14]

Provisions related to the potential withholding or withdrawal of medically supplied nutrition and hydration are especially likely to vary by state, perhaps because forgoing medically supplied nutrition and hydration tends to incite more controversy than forgoing many other treatments.[15] For example, although Connecticut's statutes do not expressly impose limitations on a surrogate or proxy decision maker's ability to authorize withholding or withdrawal of medically supplied nutrition and hydration, Oklahoma[16] and Arizona[17] impose strict limitations on such decisions in some circumstances.

Although lawyers are accustomed to such context specificity because it is common for the same term to have different meanings in different areas of the law, physicians may feel discomfort with the resulting vagueness. One way to combat that discomfort is to recognize that the variations are present in the law and to have an overall sense of where the variations appear and what they are. Toward that end, an excellent chart detailing these and more state-by-state variations in existence as of December 2006 appears in Hickman et al.[18] In addition, the American Thoracic Society Web site contains a valuable state-by-state compilation of advance directive forms,[19] and the next article in this series will address such variations in greater depth. Another way to combat the discomfort is to recognize that several state legislatures have attempted to ease concerns over such variations themselves. Some state statutes "provide that an advance directive is valid if it complies with either the law of the state in which it was executed…the law of the state in which it is to be enforced…or both."[20] Although such portability provisions do not resolve all questions, they can be helpful.

Conclusions

The law of withholding and withdrawal of treatment has much in common with medical ethics. It is based on concerns about patient autonomy expressed by courts, legislatures, and the executive branch of the government. The right to refuse life-sustaining treatment may have roots in state or federal constitutions, in tort law, or in both. Additionally, legislatures statutorily have authorized some form of advance directive in every state plus the District of Columbia, whereas state agencies and courts have contributed by interpreting those statutes.

Significant variations can exist among the states, but although technically valid, excessive concern about compliance with the precise contours of each state's statute when surrogate decision makers are engaging in bedside deliberations is unnecessary. Written evidence of patient wishes, whether complying with a state's execution formalities or precisely tracking statutory authorizations, is just that—written evidence of patient wishes. As a matter of fact and legal precedent, written evidence of patient wishes satisfies even the most exacting standard applying to decision making for incapacitated patients. It is evidence of what the patient said he or she wanted; thus, it should be taken into consideration in determining the patient's wishes regardless of whether the instrument in which the patient memorialized his or her wishes is technically perfect and whether it technically has become effective under the state's laws.

The overall goal, which neither the physician nor the patient's surrogate or proxy decision makers should forget, is to honor what the patient would want to have done. Physicians and attorneys will agree on that as a matter of both ethics and the law.

Acknowledgments

Financial/nonfinancial disclosures: The author has reported to *CHEST* that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.

References

1. Will JF. A brief historical and theoretical perspective on patient autonomy and medical decision making: part I: the beneficence model. *Chest*. 2011:139(3):669-673.
2. Will JF. A brief historical and theoretical perspective on patient autonomy and medical decision making: part II: the autonomy model. *Chest*. 2011:139(6):1491-1497.
3. *In re Quinlan*, 355 A2d 647 (NJ 1976).
4. *Cruzan v Missouri Dept of Health*, 497 US 261, 278-279 (1990).
5. *Washington v Glucksberg*, 521 US 702, 720 (1997).
6. *Bush v Schiavo*, 885 SE2d 321 (Fla 2004).
7. *In re Guardianship of Browning*, 568 SE2d 4, 12 n.9 (Fla 1990).
8. Meisel A, Cerminara KL. Table of advance directive statutes. In: *The Right To Die: The Law of End-of-Life Decisionmaking*. 3rd ed (suppl). New York, NY: Aspen Publishers; 2010:§7.13.
9. Meisel A, Cerminara KL. Bibliography. In: *The Right To Die: The Law of End-of-Life Decisionmaking*. 3rd ed (suppl). New York, NY: Aspen Publishers; 2010:§8.11.
10. Cerminara KL, Bogin SM. A paper about a piece of paper. Regulatory action as the most effective way to promote use of physician orders for life-sustaining treatment. *J Leg Med*. 2008;29(4):479-503.
11. Sabatino CP. National advance directives: one attempt to scale the barriers. *NAELA J*. 2005;1:131-164. http://www.agingwithdignity.org/forms/naela.pdf.
12. Fla Stat Ann §765.101(17).
13. Hospice care: general provision and definitions. 42 CFR §418.3.
14. Tenn Code Ann §11-32-103(9).
15. Meisel A, Cerminara KL. Other forms of treatment. In: *The Right To Die: The Law of End-of-Life Decisionmaking*. 3rd ed (suppl). New York, NY: Aspen Publishers; 2010:§6.03(G).
16. Okla Stat Ann tit 63, §3080.4(A)(1), §3101.4(B).
17. Ariz Rev Stat §32-3206.

18. Hickman SE, Sabatino CP, Moss AH, Nester JW. The POLST (Physician Orders for Life-Sustaining Treatment) paradigm to improve end-of-life care: potential state legal barriers to implementation. *J Law Med Ethics*. 2008;36(1):119-140, 144.
19. American Thoracic Society. Advanced directives state-specific directory. American Thoracic Society Web site. http://thoracic.org/clinical/critical-care/patient-information/making-decisions-about-the-end-of-life/advance-directives-state-specific-directory.php. Accessed November 23, 2009.
20. Meisel A, Cerminara KL. Miscellaneous provisions. In: *The Right To Die: The Law of End-of-Life Decisionmaking*. 3rd ed (suppl). New York, NY: Aspen Publishers; 2010: §7.10(J).