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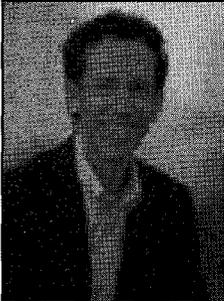
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Health Care Law: A Field of Gaps

*David Orentlicher, M.D., J.D.**



During the past twenty-five years, a number of issues in health care law have illustrated an important paradox. As Tocqueville observed more than one hundred fifty years ago in his classic study of the United States, we regularly turn to the courts to resolve our political differences.¹ Yet, many issues that seem to have been settled by the courts turn out not to be very settled. The continuing debates over abortion provide a prominent illustration. Decisions at the end of life offer important examples as well. Although courts have concluded that withdrawing life-sustaining treatment is the same as withholding such treatment and that withdrawing artificial nutrition and hydration is no different than withdrawing artificial ventilation, many people continue to hew to those distinctions.

Because critical issues may be judicially decided but publicly unsettled, health care law is very much a field of gaps—gaps between law on the books and law in practice, gaps between perceptions of law and its actual impact, and gaps between rhetoric and reality.² Perhaps these gaps are not surprising. Health care law deals with many difficult and controversial issues, issues that really can mean the difference between life and death. Still we can hope that over the next twenty-five years, these gaps might be narrowed if not bridged.

I. GAPS BETWEEN LAW ON THE BOOKS AND LAW IN PRACTICE

End-of-life decision making provides a number of examples where doctors and sometimes even judges deviate from the legal principles that seemingly have been well-established.

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1. ALEXIS DE TOCQUEVILLE, *DEMOCRACY IN AMERICA*, Chapter 16 (1835).
2. Of course, there is also the gap between the ideal laws and the laws that are enacted, but that gap is an inherent part of the political process.

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Following ethical understanding, for example, the law has rejected a distinction between withdrawing and withholding life-sustaining treatment.³ In one view, doctors have a greater obligation to maintain treatment than to initiate it, just as a bystander has a greater obligation to complete the rescue of a person in distress than to begin a rescue. This view, however, has not gained acceptance—it is clear under the law that the right to have medical treatment withdrawn is the same as the right to have treatment withheld. Nevertheless, health care providers continue to feel that it is less acceptable to withdraw care than to withhold it. The physician who discontinues artificial ventilation can easily feel more responsible for a patient's death than when ventilation is never begun.

Or consider the prevailing principle that a person's right to refuse medical treatment does not depend on the person's medical condition or the nature of the treatment being refused. The young, generally healthy adult can refuse a life-saving antibiotic just as a very old adult with widely metastatic lung cancer can refuse artificial ventilation. As courts have observed, patients and their families will want to take into account the patient's condition and the kind of medical treatment at stake in deciding whether to accept or refuse care, but the patient's right is not limited because of the patient's favorable prognosis or the minimal intrusion of treatment.⁴ Yet, doctors and judges may respond differently when faced with a young person's refusal of a blood transfusion. In Florida, for example, the state supreme court had to overturn a lower court's decision to order the transfusion of blood for a young mother even though it had overturned a lower court in a comparable case four years earlier.⁵

Similarly, even though courts have invoked common law and constitutional law principles to recognize the same right to refuse artificial nutrition and hydration as to refuse artificial ventilation or dialysis, some living will statutes make it more difficult for people to exercise their right to refuse unwanted nutrition and hydration. In addition, studies have found that physicians are quicker to recommend the discontinuation of ventilators, dialysis, and other treatments than the discontinuation of nutrition and hydration.⁶ Families are no different. Even after winning the right to have his daughter Karen's ventilator withdrawn, Joseph Quinlan did not agree to have her feeding tube withdrawn. When asked if he wanted to stop her feeding, he replied, "Oh no, that is her nourishment."⁷

3. MARK HALL, MARY ANNE BOBINSKI & DAVID ORENTLICHER, *HEALTH CARE LAW AND ETHICS* 532-33 (7th ed., Aspen Publishers 2007).

4. *Id.* at 535-37.

5. *Id.* at 544-45.

6. *Id.* at 533-34, 584.

7. Paul Ramsey, *Prolonged Dying: Not Medically Indicated*, 6(1) *HASTINGS CENTER REP.* 14, 16 (1976).

II. GAPS BETWEEN PERCEPTIONS OF LAW AND ITS ACTUAL IMPACT

Doctors frequently view the law as hostile to them, while in fact, courts (and legislatures) treat physicians quite favorably, with a high degree of deference to professional judgment. Thus, for example, physicians see the law as ever-ready to punish them when patients suffer bad outcomes, even when no malpractice occurred. However, juries are more likely to decide in favor of physicians than other personal injury defendants, judges allow physicians to determine their own standard of care, and only a small percentage of patients harmed by negligence ever sue.⁸

The law's deference to professional judgment is common throughout the law. When the Supreme Court decided that the Americans with Disabilities Act (ADA) protects persons with communicable diseases from discrimination in the workplace and other settings, it also recognized that the ADA does not prevent employers and other people from taking reasonable steps to protect themselves from infection. The Court observed further that trial courts should defer to professional medical judgment in deciding whether a person's communicable disease poses a significant risk to the health and safety of other people.⁹

Or consider the question whether doctors may withhold life-sustaining treatment even when it is desired by the patient (or the patient's family), on the ground that the treatment would be medically futile. Although courts are reluctant to grant a hospital's request to withdraw or withhold life-sustaining treatment because of futility, they regularly validate futility decisions by hospitals that have already been implemented when the family later sues for wrongful death. As one court observed, whether treatment is futile is a question of the standard of care to be determined by professional consensus.¹⁰

III. GAPS BETWEEN RHETORIC AND REALITY

Life-and-death decisions are challenging enough but especially so in a world of limited resources. When the organ transplantation system decides on the recipient of a heart or liver, when physicians decide how to allocate their time among different patients, or when insurers decide whether a novel treatment should be covered, it is difficult to explain to those who are disfavored in the process why that should be the case. And it is difficult for decision makers to acknowledge their responsibility for the outcomes. Accordingly, health care providers frequently camouflage rationing

8. HALL ET AL., *supra* note 3, at 274-75, 287-91.

9. *Bragdon v. Abbott*, 524 U.S. 624, 650 (1998); *Sch. Bd. of Nassau County v. Arline*, 480 U.S. 273, 288 (1987).

10. *Causey v. St. Francis Med. Ctr.*, 719 So. 2d 1072, 1076 (La. Ct. App. 1998).

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decisions as medical decisions,¹¹ and lawmakers support them when they do so.

Thus, for example, rather than say that dialyzing a terminally ill patient is a poor use of money and staff time, a physician might say that it is medically futile to do so. By couching the decision in medical terms, a physician delivers a message that is less susceptible to challenge by the patient or family. Moreover, medical decisions are beyond the control of the physician.¹² If treatment is withheld for “medical” reasons, it is not the physician’s fault that treatment will not be provided; it is the failure of medical science. And as indicated above, courts will support doctors and hospitals after they have withdrawn or withheld care on grounds of futility.

Consider, as well, society’s adoption of “brain death.” Leading, early proponents of brain criteria for death cited the burdens “on those in need of hospital beds already occupied by these comatose patients” as one important reason for implementing the proposal.¹³ But rather than simply say that resources are better used for patients who might recover than for patients who have irreversibly lost all brain function, society redefined the most severely brain-damaged patients as dead. Thus, these patients are denied medical care on the ground that they are medically unsuited for care rather than because they are less-deserving candidates for care.

To be sure, such subterfuges are not entirely successful. The use of medical futility to justify denials of care often provoke controversy, and the public still does not view “brain death” the same as death determined by the cessation of the heartbeat. When pregnant women are ventilated after the declaration of death by brain criteria until their fetuses are viable and can be delivered, it is common to see them described as dying on the day that the ventilator is finally removed.¹⁴ Nevertheless, the subterfuges persist or are replaced by new subterfuges, for the acknowledgement of the reality would be too unsettling.

IV. CONCLUSION

It is often said that the law lags behind developments in medicine. As I have suggested, developments in the law often outpace public sentiments and preferences. An important task for the next twenty-five years will be to understand better the nature of the gaps between health care law and the public’s views and to figure out how to bridge those gaps. I expect the

11. GUIDO CALABRESI & PHILIP BOBBITT, TRAGIC CHOICES 18, 64-66 (1978).

12. DAVID ORENTLICHER, MATTERS OF LIFE AND DEATH 160-61 (2001).

13. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 JAMA 85, 85 (1968).

14. Richard Willing, *Brain-Dead Woman Dies After Baby Born*, USA TODAY, Aug. 4, 2005, at 3A.

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Beazley Institute for Health Law and Policy to play a key role in this endeavor, as it has in health care law for the past twenty-five years.