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## Gang Aft Agley

Carl E. Schneider

*University of Michigan Law School, carlschn@umich.edu*

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# Gang Aft Agle

by Carl E. Schneider

*The amount of law is relatively small which a modern legislature can successfully impose. The reason for this is that unless the enforcement of the law is taken in hand by the citizenry, the officials as such are quite helpless. . . . For what gives law reality is not that it is commanded by the sovereign but that it brings the organized force of the state to the aid of those citizens who believe in the law.*

—Walter Lippmann  
*A Preface to Morals*

In my last contribution to this column (*HCR*, July-August 2000), I argued that the law of bioethics has repeatedly failed to achieve the hopes cherished for it. I presented evidence, for example, that most doctors breach the duty of informed consent, that advance directives do not direct patients' care, and that repeated legal attempts to increase organ donation have failed to find the success predicted for them. I closed that column by promising to try to explain this chastening experience.

It would, of course, take a lifetime of columns to capture all the reasons the law of bioethics has so often disappointed.<sup>1</sup> Here I want to discuss only one, albeit a crucial one: Legal regulation of human behavior is insistently difficult because human behavior and social institutions are bafflingly complex. It is maddeningly hard to mold that behavior and those institutions because they are shaped by many potent forces besides the law and because lawmakers so often cannot accurately identify all those forces and devise reliable methods of altering enough of them in sufficiently

precise and predictable ways to achieve the result intended. It is even hard for law to rule in its own house—for example, to shape litigation in useful ways. The law of bioethics illustrates both the general problem (influencing social behavior) and its particular instantiation (influencing legal institutions). Let me once again adduce empirical evidence to show how.

Living wills exemplify the first problem. Living wills seemed an obvious solution to the perplexity of making end of life decisions for incompetent patients, but they have betrayed the expectations faithfully nurtured for them. To see why, consider the chain of circumstances necessary for living wills to be well and widely used.

First, people must want a living will. Some people say they do not, many of them because they think satisfactory decisions will be made for them without one. Many people believe they want a living will, but very many of these have not signed one even though they know about advance directives. Programs to persuade people to sign living wills have not been conspicuously successful. Is this, perhaps, because people do not actually want them, or do not actually want them enough to overcome ambivalence about them?

Second, people must know what treatment they would want should they become incompetent. This requirement has several components. To begin with, people must (a) obtain accurate information about what their choices would be and (b) understand that information. But patients will encounter all the prob-

lems acquiring and analyzing information that have become notorious through studies of informed consent. And empirical investigation suggests that doctors are neither anxious to have conversations about living wills nor adept at conducting them.<sup>2</sup> Furthermore, unless people are assisted with exceptional care, they must decipher the advance directive itself. This is no small undertaking. Living wills are often execrably drafted. And even if they were drafted by angels, “[i]n the largest study of functional health literacy in the United States, . . . 42% of . . . [English-speaking patients] were unable to comprehend directions for taking medication on an empty stomach, 26% could not understand information on an appointment slip, and 60% could not understand a standard consent form.”<sup>3</sup> In addition, people preparing advance directives not only confront all the perplexities of medical decisions; they also face the special problems of making decisions for a hypothetical future. They must imagine what they would want at an unspecifiable time stricken with an unidentifiable illness with unpredictable treatments.

People who have come this far must, third, put their choices into words. This riddle has received considerable, pained, attention. The first generation of living wills spoke in egregiously broad terms; the second generation reacted with heroic attempts at specificity; and the third generation has essayed such devices as “values histories,” recklessly flouting Oliver Wendell Holmes’s wise warning that “general principles do not decide concrete cases.” My own experience is that patients cannot tell you what their living wills actually say, and more systematic students conclude, for example, that their “observations raise serious questions about the patient’s understanding of the general statement in the California directive and suggest that such brief expressions cannot be taken as exact instructions.”<sup>4</sup>

Fourth, the living wills patients write must be available to the people making the medical decisions. Ordinarily, this means living wills must leave the lawyer’s or doctor’s office, follow pa-

tients in their pilgrimage through the health care system, and enter patients' charts in sufficiently obvious ways that they are noticed. We thus find studies reporting, for example, that in 74 percent of the admissions examined, "the advance directive was not recognized, nor was there written documentation of any attempts to discern if an advance directive had been previously executed."<sup>5</sup>

Fifth, the people making decisions for incompetent patients must comprehend and obey the living will's instructions. The challenges this requirement presents are suggested by the study that found that "[e]ven with the therapy-specific A[dvance] D[irective] accompanied by designation of a proxy and prior patient-physician discussion, the proportion of physicians who were willing to withhold therapies was quite variable."<sup>6</sup> Another study determined that "the existence of an advance directive that limits the therapeutic maneuvers to be carried out after the patient becomes unable to make his or her own healthcare decisions do [*sic*] not influence the level of medical care overall."<sup>7</sup> As another study explained, there is "a complex interaction of the following three themes: patients were not seen as 'absolutely, hopelessly ill,' and thus, it was never considered the time to invoke the AD; the contents of ADs were vague and difficult to apply to current clinical situations; and family members or the surrogate designated in a [durable power of attorney] were not available, were ineffectual, or were overwhelmed with their own concerns and did not effectively advocate for the patient."<sup>8</sup>

In sum, failures confound every step along the path toward a successful regime of advance directives and show how challenging it can be for the law to affect behavior even in apparently simple and desirable ways. The similarly perilous path to a law of informed consent with bite indicates that the law can

hardly make even its own institutions work as intended. The law gives doctors an incentive to inform their patients properly by offering patients a legal remedy—money damages—if physicians fail in their duty. But observe again how many steps lie between the injury and the remedy. First, patients must realize both that they have not been informed as the law requires and that they have legal recourse. Then they must decide to sue. We may be a litigious society, but even people who have actually been injured often decline to pursue legal remedies. For example, "only a small fraction of persons with a valid [medical malpractice] claim actually file a suit."<sup>9</sup> Having decided to sue, patients must find a lawyer.

But this is the easy part. Lawyers ordinarily ask three questions: Did the doctor's failure to inform the patient cause some physical injury? Would the ordinary patient have chosen a treatment differently if properly informed? Was the injury great enough and is the evidence clear enough to make it worth my while litigating the case? To at least one of these questions, the answer is usually "no." Even if the answer to each is "yes," patient and lawyer must persevere over the many years suits last. The court must accurately evaluate the doctor's liability and the patient's damages. Finally, doctors must extract the correct lessons from the law's workings: they must learn when information is required and that withholding it exacts appropriately measured costs.

In short, the law of bioethics disappoints partly because it is truly difficult to affect human behavior. Not only is life elaborately complex. People's preferences and behavior are principally shaped by the norms and institutions in which they are embedded. The law can wheel its cumbersome and rickety machinery into place only laboriously and sporadically. Small wonder that law gen-

erally, and not just the law of bioethics, repeatedly teaches us that "[t]he amount of law is relatively small which a modern legislature can successfully impose."

But I do not counsel despair. Law's policies can be devised badly or well. In a later column I will discuss some of the reasons lawmakers seem so often to have written the law of bioethics ineptly.

1. I have already described several reasons in "Bioethics in the Language of the Law," *Hastings Center Report* 24, no. 4 (1994): 16-24. There I argued that law and bioethics speak different languages because law is a general system of social regulation that responds to many imperatives beyond bioethical reason.

2. See, for example, J.A. Tulsky et al., "Opening the Black Box: How Do Physicians Communicate about Advance Directives?" *Annals of Internal Medicine* 129 (1998): 441-49, at 444.

3. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association, "Health Literacy: Report of the Council on Scientific Affairs," *JAMA* 281 (1999): 552-53, at 553.

4. L.J. Schneiderman et al, "Relationship of General Advance Directive Instructions to Specific Life-Sustaining Treatment Preferences in Patients With Serious Illness," *Archives of Internal Medicine* 152 (1992): 2114-22, at 2119.

5. R.S. Morrison et al., "The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings," *JAMA* 274 (1995): 478-82, at 480.

6. W.R. Mower and L.J. Baraff, "Advance Directives: Effect of Type of Directive on Physicians' Therapeutic Decisions," *Archives of Internal Medicine* 153 (1993): 375-81, at 378.

7. M.D. Goodman, M. Tarnoff, and G.J. Slotman, "Effect of Advance Directives on the Management of Elderly Critically Ill Patients," *Critical Care Medicine* 26 (1998): 701-704, at 703.

8. J.M. Teno et al., "Role of Written Advance Directives in Decision Making: Insights from Qualitative and Quantitative Data," *Journal of General Internal Medicine* 13 (1998): 439-46, at 441.

9. F.A. Sloan et al, *Suing for Medical Malpractice* 1 (University of Chicago Press, 1993), p. 1.