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The Best-Laid Plans

by Carl E. Schneider

It is natural to suppose law is like the centurion and can do as it will: “I say to this man, Go, and he goeth; and to another, Come, and he cometh; and to my servant, Do this, and he doeth it.” But a thousand years ago, King Canute tried to disillusion his courtiers about his efficacy by commanding the waves to stop beating. And fifty years ago, Harry Truman predicted of Dwight Eisenhower, “He’ll sit here, and he’ll say, ‘Do this! Do that!’ *And nothing will happen.* Poor Ike—it won’t be a bit like the Army. He’ll find it very frustrating.”

It is natural to suppose law can do as it will because law has imposing powers. It can spend. It can fine. It can imprison. It can kill. So armed, surely it can command obedience. Sometimes it can. But surprisingly often, laws disappoint. They rarely fail completely. But, with dismaying frequency, laws betray the expectations of their promulgators and their advocates.

The law of bioethics is no exception. In recent decades, courts and legislatures have put several central bioethical ideas into law. These reforms seemed surpassingly logical. Yet today many of them look puzzlingly ineffectual. A new study of informed consent typifies the results that dismay. Clarence Braddock and his colleagues taped 1,057 encounters between doctors and patients. Their report: “Overall, the completeness of informed decision making was low. . . . [F]ew decisions (9.0%) met criteria for completeness of informed decision making.” The authors thought their

“findings suggest that the ethical model of informed decision making is not routinely applied in office practice” and that the “low level of informed decision making suggests that physicians’ typical practice is out of step with ethical ideals.”¹

The Braddock study is all too easily duplicated in other contexts. It examines what doctors tell patients. Other studies investigate the forms used to obtain consent and found them opaque. Yet other studies tested patients after they received information and find they have trouble remembering and understanding what they are told. Still other studies are gloomy about efforts to warn prospective subjects of medical experiments that they are unlikely to benefit therapeutically from participating. As one summary puts it, studies “have shown that patients remain inadequately informed, even when extraordinary efforts are made to provide complete information and to ensure their understanding.”²

Informed consent is perhaps the oldest of these attempts to put bioethical principles into law. It is also one of the best accepted; who today would appear in print to denounce giving patients the information they need to make decisions? If informed consent disappoints, what legal reform can hope to do better?

But informed consent is not alone in disappointing. Advance directives quickly found legal favor when they were proposed, yet their promise remains unrealized. Most people do not have an advance directive. Even people

who have particular reason to use them do so less frequently than commentators want: “Although chronic dialysis patients support and favor advance directives in principle, only 28% to 38% of dialysis patients complete advance directives.”³ Even when advance directives are signed, they are not always available when needed. One inquiry discovered that only a quarter of the advance directives incompetent patients executed were documented somewhere, somehow in the patient’s chart.⁴ And even when advance directives are available, it is unclear how well they work. One study even found care was, perversely, *less* likely to be consistent with patients’ previously expressed wishes when the advance directive was available.⁵ Thus one of the SUPPORT studies concluded that “standard living wills do not effectively direct care decisions for seriously ill adults.”⁶

The Patient Self-Determination Act “was enacted specifically because so few individuals complete advance directives and because ‘the living will, and its close relative, the durable power of attorney [were] counted as abject failures with respect to the protection of autonomy.’”⁷ The PSDA essentially requires medical institutions to tell patients about advance directives. Hospitals have responded with “very passive and limited implementation strategies,”⁸ and the statute seems to have made little difference. One commentator even suggests that “the PSDA, rather than promoting autonomy, has ‘done a disservice to most real patients and their families and caregivers.’ It has promoted the execution of uninformed and under-informed advance directives, and has undermined, not protected, self-determination. The PSDA looks like an utter failure.”⁹

Informed consent and advance directives are two crucial areas of disappointment. There are others. Legal reforms to boost the number of organ donors have not yielded their expected fruits. Laws regulating DNR orders have proved difficult to make effective. Legally recognizing brain death looked simple, since that reform was initiated by and directed to physicians. Yet years later a survey

of doctors “most likely to be in a position to declare death in potential [organ] donors” and of doctors and nurses “likely to be involved with organ donors” found that only 35 percent “both knew the whole-brain criterion of death and were able to apply it correctly to identify the legal status” of two categories of patients.¹⁰

One common response to these disappointments is to say that the law is good but badly applied. This tactic commonly leads to a continuing spiral of new and ever more ambitious proposals to make the good idea work. For example, when it became plain that the first, innocently simple, generation of advance directives was too vague to guide decisions lucidly, a more elaborate second generation was devised. When it was then suggested that the second generation required unrealistically detailed yet still incomplete choices, a third generation of advance directives strove to capture patients’ “values.” Because dissatisfaction persists, proposals to stimulate more and better conversations between doctors and patients about end of life treatment are often mooted. Yet one study of such conversations concluded that although they “accomplished the goal of introducing patients to the topic of advance directives, their usefulness in future decision making seems limited.”¹¹

The law of informed consent has followed a similar trajectory. Courts introduced it with pleased confidence. As disenchantment grew, various reforms were suggested to give the law more bite (by, for example, letting patients sue even when the failure to inform does not lead them to make an injurious decision). Eventually, plans of utopian splendor came to seem necessary. We now hear that informed consent cannot truly work unless: (1) It is “individualized” and includes an “in-depth exploration by providers of patients’ affective and cognitive processes.” (2) Doctors “explore uncertainties and limitations both in the provider’s own knowledge and in the state of the science.” (3) “[P]roviders . . . understand and disclose their own motivations, beliefs, and values to patients.” (4) Doctors find out what role patients want in decisions. (5) Informed

consent is solicited “in the context of an ongoing relationship with a trusted health care provider.”¹²

Another common response to law’s disappointments is to argue that laws succeed indirectly: that while a law may be flouted, its spirit is followed. Doctors may not heed the forms of consent law, but perhaps it has led them to give patients information more generously and to defer to patients’ preferences more softly. Advance directives may be used less than expected, but perhaps doctors discuss treatment at the end of life with their patients more willingly, and perhaps patients consider and announce what they want more readily.

These arguments probably contain some important truth. However, they are wonderfully hard to evaluate. Assume doctors and patients actually are talking with each other more about end of life decisions. Did the law actually promote those conversations? Doctors and patients may be talking more for many reasons. Indeed, the cultural developments that made advance directives alluring—a burgeoning belief in patient autonomy, a growing feeling that people were being overtreated at the end of life—would probably have encouraged conversation whatever the law said. That is, the same cultural forces that impelled the legal reform may be driving the conduct these arguments attribute to the reform.

Much the same can be said about informed consent. Patients are doubtless getting more information than before. But is that because the law requires it? Because patients ask for it? Because medical wisdom increasingly thinks it therapeutically desirable to inform patients better? Because doctors believe they reduce the risk of being sued for malpractice if they defer to patients’ choices?

I do not wish to be misunderstood. I am not saying that law never accomplishes anything, or even that it never accomplishes what it intends. I am not saying legal reforms are never worth essaying. I am saying that law repeatedly disappoints. It is not obvious how we should respond to this observation. One reasonable response is to ask whether

our standards of evaluation are too high and to explore what it is reasonable to ask of law. Another is to consider what tools besides law might better serve our ends. Yet another is to ask how we might make our predictions about a rule’s success more accurate and thus make our cost-benefit analyses of it more cogent. But all these responses depend on knowing *why* law so often disappoints. Happily, there are some systematic answers to that question. To them I will turn in my next column.

1. Clarence H. Braddock, et al., “Informed Decision Making in Outpatient Practice: Time to Get Back to Basics,” *JAMA* 282 (1999): 2313-2320, at 2317 and 2319.

2. Barrie R. Cassileth, et al., “Informed Consent—Why Are Its Goals Imperfectly Realized?” *NEJM* 302 (1980): 896-900, at 896.

3. Jean L. Holley et al., “Factors Influencing Dialysis Patients’ Completion of Advance Directives,” *American Journal of Kidney Diseases* 30 (1997): 356-60, at 356.

4. R. Sean Morrison, et al., “The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings,” *JAMA* 274 (1995): 478-82.

5. Marion Danis et al., “A Prospective Study of Advance Directives for Life-Sustaining Care,” *NEJM* 324 (1991): 882-888, at 884.

6. Joan M. Teno et al., “Do Advance Directives Provide Instructions That Direct Care?” *Journal of the American Geriatrics Society* 45 (1997): 508-512, at 508.

7. Thaddeus Mason Pope, “The Maladaptation of Miranda to Advance Directives: A Critique of the Implementation of the Patient Self-Determination Act,” *Health Matrix* 9 (1999): 139-202, at 155-56.

8. Jeffrey L. Yates and Henry R. Glick, “The Failed Patient Self-Determination Act and Policy Alternatives for the Right to Die,” *Journal of Aging & Social Policy* 9 (1997): 29-50, 32.

9. See ref. 7, Pope, “The Maladaptation of Miranda,” at 167.

10. Stuart J. Youngner, et al., “Brain Death’ and Organ Retrieval: A Cross-sectional Survey of Knowledge and Concepts among Health Professionals,” *JAMA* 261 (1989): 2205-2210, at 2207-10.

11. James A. Tulsky, et al., “Opening the Black Box: How Do Physicians Communicate About Advance Directives?” *Annals of Internal Medicine* 129 (1998): 441-449, at 446.

12. Gail Geller et al., “Decoding’ Informed Consent: Insights from Women Regarding Breast Cancer Susceptibility Testing,” *Hastings Center Report* 27, no. 2 (Mar/Apr 1997): 28-33.