

AFTER AUTONOMY

*Carl E. Schneider**

To rest upon a formula is a slumber that, prolonged, means death.

Oliver Wendell Holmes, Jr.
Ideals and Doubts

I. INTRODUCTION

The communists . . . are on the one hand, practically, the most advanced and resolute section of the working-class parties of every country, that section which pushes forward all others; on the other hand, theoretically, they have over the great mass of the proletariat the advantage of clearly understanding the line of march, the conditions, and the ultimate general results of the proletarian movement.

Karl Marx & Friedrich Engels
The Communist Manifesto

Bioethicists¹ today are like Bolsheviks on the death of Lenin.

* Chauncey Stillman Professor of Law and Professor of Internal Medicine, University of Michigan. I am grateful to the editors of the Wake Forest Law Review for bravely and generously permitting me to abandon the conventions of law review editing. They have duly pointed out the errors of form and style that you are about to encounter, and I cheerfully relieve them of all responsibility for every solecism. For a justification of my willfulness and an invitation to my colleagues to join me in it, see Carl E. Schneider, *The Book Review Issue: An Owner's Manual*, 96 Michigan L Rev 1383 (1998). For the reasons given in Richard A. Posner, *Goodbye to the Bluebook*, 53 U Chicago L Rev 1343 (1986), I follow the University of Chicago *Manual of Legal Citation* (Lawyers Co-operative, 1989).

From first to last, Mark Hall has been the but-for cause of this essay. I proffer him all the thanks at my command, provided that he pass her fair share on to Diana. It is also a pleasure to thank the participants in the Wake Forest workshop for their perceptive comments on this essay. Rebecca Dresser was specifically assigned to comment on it, and she showed yet again why she is one of the most valuable and admirable people in bioethics.

1. I need a shorthand word for a varied group. So by bioethicists I mean people who practice and write about bioethics generally, people who write about the legal regulation of bioethical issues, and people who write such regulations. This group obviously varies from category to category and within categories.

They have, rather to their surprise, won the day. Their principle of autonomy is dogma. Their era of charismatic leadership is over. Their work of Weberian rationalization, of institutionalizing principle and party, has begun. The liturgy is reverently recited, but the vitality of Lenin's "What Is To Be Done?" has yielded to the vacuity of Stalin's "The Foundations of Leninism." Effort once lavished on expounding ideology is now devoted to establishing associations, organizing degree programs, installing bioethicist commissars in every hospital, and staffing IRB soviets. Not-so-secret police prowl the libraries hunting counter-revolutionaries and other wreckers; anxious academics denounce deviationist colleagues. A field once comprising diverse people from diverse backgrounds with diverse perspectives is increasingly populated by standard academics with standard academic opinions.

Nevertheless, the *samizdat* literature persistently asserts that the policy of autonomy is betraying its promise. Explication of the autonomy principle is becoming repetitive and arid. Programs always need one more revision, one more Five Year Plan, before they can actually begin to work. Life in the vanguard of the (patient) proletariat grows irksome when the proletariat is so balky and ungrateful. Surely somewhere the next great bioethical idea is slouching toward Moscow to be born.

The bioethical *apparat*, of course, insists that the only cure for the ills of autonomy is more autonomy. The *apparat* not only reiterates the principle; it has raised the stakes in two ways. First, as it has become undeniable that in area after area patients remain far from making genuinely autonomous decisions, the list of things doctors, hospitals, and researchers must do if they are really and truly to honor patients' autonomy grows and grows. One modest proposal, for instance, demands that patients be told not only the benefits and risks of proposed treatments but also imagines that (take a deep breath):

- (1) "Providers" should undertake an "in-depth exploration" of patients' "affective and cognitive processes."
- (2) Providers should "explore uncertainties and limitations both in the provider's own knowledge and in the state of the science."
- (3) "[P]roviders must understand and disclose their own motivations, beliefs, and values to patients."
- (4) "[P]roviders ought to explore what kind of role

Academic bioethicists range from quite sophisticated to quite dogmatic. Clinical bioethicists tend more toward the rustic. Courts, legislatures, and agencies can seem hardly subtler. See Marsha Garrison & Carl E. Schneider, *The Law of Bioethics: Individual Autonomy and Social Regulation* (West, 2002).

expectations [about how decisions should be made] the patient has for herself and her provider.”

(5) “[I]nformed consent ought to be individualized . . . and take place in the context of an ongoing relationship with a trusted health care provider.”²

In what world could all this happen? And in that world, would patients *then* make autonomous decisions?

The second way the stakes are being raised for the autonomy principle is by the gradual acceptance of “mandatory autonomy.” This is the idea that patients not only are entitled to make their own decisions but have an ethical or social duty to do so.³ In its most robust form, mandatory autonomy still has relatively few avowed proponents, but increasingly potent versions of it increasingly appear in the writings not just of bioethicists, but also of doctors and patients (and, floridly, in the medical students I teach).⁴

Yet between the idea and the reality falls the shadow. Even while the *apparatus* raises the stakes for autonomy, discontent with its predominance proliferates. No one rejects autonomy entirely, but at the level of theory two criticisms are now long standing. The first criticism acknowledges the value of the principle but suggests that competing principles are too regularly scanted. (And now abide beneficence, social justice, and autonomy, these three; but the greatest of these is autonomy.) The second criticism contends that the autonomy principle, while estimable and essential, promotes deleterious attitudes, perhaps principally by underwriting a corrosive individualism that alienates people from their family, friends, and physicians.

These criticisms are apt, but they hardly relieve the suffocating hegemony of the autonomy principle. That principle is too well entrenched, and the criticisms offer no substitute for it, much less a substitute with ready appeal. They do not even offer satisfying complements to it. The criticisms acknowledge the necessity of the autonomy principle and only want to confine it to its proper sphere. Yet what is that sphere and how should autonomy be modulated and offset by other principles? Little can be said in the abstract; little gets said in concrete cases.

The problem is not just intellectual; it is political. Bioethics was born a reform movement and adamantly remains one. It is a movement with an enemy—medical imperialism. Such movements welcome intellectuals only as long as they are politically useful; they

2. Gail Geller et al, “Decoding” *Informed Consent: Insights from Women Regarding Breast Cancer Susceptibility Testing*, Hastings Center Report 28 (March/April 1997).

3. I investigate this idea at length in *The Practice of Autonomy: Patients, Doctors, and Medical Decisions* (Oxford U Press, 1998).

4. This idea too I explore at length *ibid*.

loathe renegades. He that is not with me is against me: and he that gathereth not with me scattereth. And the autonomy principle is a political symbol as well as the *fons et origo* of the faith. Concessions on matters of symbol are dangerous.

It is time for *glasnost*. No field should go for decades without rigorous self-scrutiny, and bioethics has been oddly incurious about itself. But how do we make self-examination productive? Many approaches are necessary, no single one suffices, if only because the field is such a patchwork of subjects, disciplines, and problems. Here I want to suggest one starting point. Bioethics may be the study of ethical problems, but bioethicists have always wanted to shape public policy. If that is the goal of bioethics, the first step in evaluating it is to ask whether bioethical policy is successful. Wherefore by their fruits ye shall know them.

But how are we to evaluate bioethical policies? There is a standard answer to this question—do the programs' benefits exceed their cost? This is a question I can hardly remember a bioethicist posing. For example, bioethics was born insisting that researchers regularly abused their subjects. The solution was the IRB. Today, thousands—tens of thousands?—of people whose time is ruinously expensive spend hundreds of thousands—millions?—of hours reviewing thousands and thousands of research proposals. How many ethically intolerable proposals are caught, and how many make it through the gauntlet? How many useful and harmless proposals are delayed or destroyed? The costs of IRBs are immediately obvious and obviously large. The marginal benefits could be great but may well be small. And there must be cheaper means of achieving the goal.

Consider another centerpiece of bioethics—informed consent. The seminal case of *Canterbury v. Spence* blandly (but quite typically) instituted a new legal regime of informed consent without betraying a drachma's worth of interest in whether its gains justified its costs. And who asks whether the prolonged and extensive effort to promulgate living wills is worth the candle? In short, it is a poor policy discipline that is more devoted to extending principles to their logical conclusions than to finding the right balance among conflicting goods and the right distribution of social costs, yet bioethics is that discipline.

Bioethicists ignore these questions partly because they believe—more or less explicitly—that cost-benefit analysis is wrong. This belief seems to have two bases. First, bioethical programs serve such ineffable goals that it would be wrong to think of them in economic terms. This may be what the Department of Health and Human Services had in mind in its rationale for its ruinous HIPAA regulations. HHS grudgingly conceded that the “costs and benefits of a regulation must, of course, be considered as a means of identifying and weighing options.” But in the same paragraph HHS warned that, because privacy is a “fundamental right . . . it must be

viewed differently from any ordinary economic good.”⁵ Here bioethicists are poorly served by the grandiosity of the terms in which they peddle their proposals. How can you criticize, much less abandon, a program, however expensive, that purports to enhance human rights? What is money compared with human dignity? The problem, of course, is that so many programs can be justified in similarly grand terms that we cannot possibly afford them all. The issue is not whether to pursue lofty goals; it is how to pursue them efficiently so that we can husband our resources for the many lofty calls made on them. And no goal, however worthy, justifies ineffective programs.

The second bioethical objection to cost-benefit analysis seems to be that it works badly. There is much in this criticism, to be sure. Benefits and costs are hard to measure, since they are often diffuse and sometimes hard to monetize. But this does not mean that no insights can be gained by careful and clever attempts to weigh costs and benefits. And what is the alternative to such analysis? Policy-making unable to eliminate even the most outrageous expenses and ineffective programs is doomed to foolishness and fatuity. Finally, if bioethicists really believe that the costs and benefits of programs cannot ever be intelligently assessed, surely they should doubt their ability to understand the world well enough to write regulations for it in the first place. The difficulty of cost-benefit analysis should be a constraint on law-making, not *carte blanche*.

If we are to assess the costs and benefits of bioethical programs, we need to identify their goals. These are numerous, but if we reflect on the (very central) aspects of bioethics that deal with the patient,⁶ one fact stands out: at the heart of bioethics and bioethical policy has been the effort genuinely to confide decisions to patients and genuinely to equip patients to make them competently. This is the *summum bonum* of the bioethical agenda in area after area.

For example. Most medical decisions involve contemporary treatment decisions for competent patients, and the centerpiece of bioethical policy—informed consent—has generally been expected to equip patients to make their own decisions about how to be treated and whether to participate in research. So powerful has that idea been that, for example, it has in only a few decades obliterated ancient ideas about treatment at the end of life. Thus assisted suicide has gone in my lifetime from being unthinkable to being taken seriously as a constitutional right, becoming law in one state, and nearly becoming law in several others.

5. Department of Health and Human Services, Standards for Privacy of Individually Identifiable Health Information, 65 Federal Register 82462, 82464 (2000). On the regulations, see Carl E. Schneider, *HIPAA-crazy*, Hastings Center Report 11 (January/February 2006).

6. Another shorthand term. I include in it anyone who must make a decision about receiving medical attention, not least a research subject.

More recently, bioethical policy has sought to extend the authority of patients by permitting them to make decisions in a competent today for an incompetent tomorrow, through advance directives. And when contemporaneous medical decisions must be made for formerly competent patients, bioethical policy has largely wanted surrogates to try to duplicate the decision the patients would have made.

Even bioethical policy about reproduction has been based on views about the moral and constitutional significance of the pregnant woman as decision-maker. This was (apparently) at the core of *Roe v. Wade*. And even critics of that case sometimes adopt the language of decision. Thus some states have tried to specify information women seeking abortions must be given about fetal life and alternatives to abortion.

Another kind of medical decision is currently becoming prominent—"consumer-directed health care." As health-care financing recalcitrantly continues to puzzle us, as managed care stubbornly seems to disappoint, lustrous hopes are cherished that all will finally be well if decisions can be transferred to patients. If only patients can purchase health insurance adapted to their wants and make cost part of their treatment decisions, will they not get better care at saner cost?⁷

In sum, bioethical policy has centrally aimed at confiding more and more medical decisions to more and more kinds of patients in more and more kinds of ways. But bioethical policy has not just sought to provide patients with the authority to make decisions; it has also labored to assure them the wherewithal—especially the information—to make decisions wisely: Patients' consent to treatment and participation in research is supposed to be informed. The PSDA demands that patients be told about advance directives. HIPAA requires that patients be elaborately notified of privacy policies. Ambitious provisions are being made for supplying information to purchasers of health plans and medical care. And so on.

Bioethics, in short, has a core agenda of some coherence. How, then, if we evaluate bioethics by assessing not the merits of the principle it professes but the success of the policies it promotes? What are the fruits of the program to equip patients to make the health-care decisions that affect them? It is through this question that I propose that we re-examine bioethics. The best way to refresh bioethics is not to grope for a new organizing principle, but rather to assess the content and consequences of bioethics' agenda. If that agenda is succeeding, bioethics need not be reconceived. If that agenda has largely failed, we will have added reason to reconceive

7. For a good review of these developments, see Mark A. Hall, *Paying for What You Get and Getting What You Pay For: Legal Responses to Consumer-Driven Health Care*, 69 *Law & Contemporary Problems* (forthcoming 2006).

bioethics, have evidence about the sources of bioethics' weaknesses, and have hints about directions for a new bioethics. If a new bioethics is necessary. And possible.

II. THE FAILURE OF THE AUTONOMY POLICY: SAMPLING THE EVIDENCE

For which of you, intending to build a tower, sitteth not down first, and counteth the cost, whether he have sufficient to finish it? Lest haply, after he hath laid the foundation, and is not able to finish it, all that behold it begin to mock him . . .

Luke 14:28-29

At this point, I confront a problem: I anticipate that evaluating the success of bioethical policy will identify such crushing problems that a new agenda might emerge from the inquiry. But we can't be sure until the evaluation is done. That will take many years and much effort, if it happens at all. So why should we think the inquiry will justify its costs and engender new understandings of bioethics? The short answer: There is already evidence that a perilously large part of the bioethical agenda has fallen intolerably and irremediably short of the expectations that inspired and would justify it. In this little essay I can hardly begin to touch on the (truly) thousands of relevant studies; they will be surveyed in the book I am writing. So for now, a few woefully abbreviated examples.

A. *Informed Consent*

And truly it demands something godlike in him who has cast off the common motives of humanity and has ventured to trust himself for a taskmaster. High be his heart, faithful his will, clear his sight, that he may in good earnest be doctrine, society, law, to himself, that a simple purpose may be to him as strong as iron necessity is to others!

Ralph Waldo Emerson
Self-Reliance

Consider first informed consent, perhaps the oldest and most basic legal implementation of bioethical principles. What would it take for informed consent to equip patients to make medical decisions adequately? First, doctors would have to give patients information. Second, patients would have to hear, understand, remember, and assimilate the information. Third, patients would have to analyze the information critically and insightfully. Alas, the evidence mauls the long-nurtured hopes about each of these points.

1. *Informing Patients*

The first requirement of informed consent is that doctors inform patients. Do they, after all these years? The evidence is disheartening. Braddock et al⁸ recently studied discussions between doctors and patients, looking particularly at “(1) the patient’s role in decision making, (2) the nature of the decision, (3) alternatives, (4) pros (benefits) and cons (risks) of the alternatives, (5) uncertainties associated with the decision, (6) an assessment of the patient’s understanding of the decision, and (7) an exploration of the patient’s preferences.” In a nutshell, “the completeness of informed decision making was low. . . . [F]ew decisions (9.0%) met criteria for completeness of informed decision making. Completeness of discussion of decisions varied by decision complexity. Whereas 17.2% of basic decisions were complete, none of the intermediate and only 1 (0.5%) of the complex decisions were complete.”

Variation was considerable: “Patients were often told the nature of the intervention (basic, 66.1%; complex, 83.9%), but there was seldom discussion of alternatives (5.5%-29.5%), pros and cons (2.3%-26.3%), or uncertainties associated with the decision (1.1%-16.6%). Physicians occasionally discussed the patient’s role in decision making (5%-18.4%) and elicited patient preferences (17.8%-27.2%). Physicians rarely explored whether patients understood the decision (0.9%-6.9%).” The only good news was that generally, the more complex the decision, the more thorough the discussion. “The most striking increases were in alternatives (5-fold increase), pros and cons (10-fold increase), and uncertainties (16-fold increase). Discussion of the patient’s role, discussion of the nature of the decision, and ascertainment of patient preference also showed significant increases from basic to complex categories”

2. *Understanding Information*

Even if doctors somehow informed patients thoroughly, patients would have to understand what they are told. Here, the data are also dismaying. Ponder the Herz study of 106 patients facing “routine neurosurgical procedures.”⁹ Twenty-two of them “underwent anterior cervical discectomy and interbody spinal fusion procedures, and 84 underwent lumbar laminectomies.” Patients were educated in three stages (that were apparently developed “in collaboration with a doctoral level lay educator”). First, the physician explained “the spinal anatomy and physiology,” the procedure, the “reasons for considering surgery,” the surgical techniques, the non-surgical alternatives to the procedure, and the

8. Clarence H. Braddock et al, *Informed Decision Making in Outpatient Practice: Time to Get Back to Basics*, 282 JAMA 2313 (1999).

9. David A. Herz et al, *Informed Consent: Is It a Myth?*, 30 Neurosurgery 453 (1992).

“[o]perative goals and aspects of postoperative care.” The surgeon used “printed materials and anatomical models” to make his points more clearly, he invited questions, and he asked patients to describe in their own words what they had learned.

Second, patients and their families and friends were invited to an “education conference, performed by a Master’s level nurse educator, covering the same topics.” Like the surgeon, the nurse used visual aids, solicited questions, and tried to test patients’ understanding orally. Third, patients spoke again with the surgeon. “There was further opportunity to ask questions and receive information regarding any perceived gaps in knowledge.”

Directly after meeting with the nurse, patients were tested on what they learned. When given multiple-choice questions, patients answered 53.1% of the questions correctly. Asked open-ended questions, patients’ scores sunk to 34%. Better educated patients had higher scores than less well educated patients, but even patients “with graduate education” scored only 64.8% and 36.5% (multiple choice and open-ended, respectively). More particularly, scores on questions about the nature of the illness and details of the proposed surgery were 67% and 52%. Scores on questions about the risks of the surgery were 50% and 22.8%. Scores on questions about post-operative care were 26.7% and 43%. And scores on questions about the goals and benefits of the surgery were 35% and 26%.

The Herz study investigates an exceptionally energetic, exhaustive, and exhausting attempt to inform patients, an attempt that could not be replicated in the ordinary clinical setting. Fischer et al describe a somewhat more realistic situation.¹⁰ Physicians with a mean age of thirty-seven and a mean of 11 years of experience were asked to “discuss ‘advance directives’” with some of their own patients (whom they had known for an average of two and a half years) who were either at least sixty-five or suffering from a serious illness. Only 70% of these conversations mentioned CPR. “The patients who had these discussions greatly overestimated their chances of survival after an in-hospital cardiopulmonary arrest.” Their “median estimate of the probability of survival to hospital discharge was 70%, compared with a 20% median probability of survival stated by their physicians.” There were “no significant differences in responses between patients” who had discussed CPR and those who had not when they were asked whether people usually need a ventilator after CPR.

The bad news marches on: “Patients whose discussions included mechanical ventilation had a poor understanding of what this procedure entails, and a significant number harbored important misconceptions. . . . No [*sic*] subject who discussed ventilators had a

10. Gary S. Fischer et al, *Patient Knowledge and Physician Predictions of Treatment Preferences After Discussion of Advance Directives*, 13 J General Internal Medicine 447 (1998).

good understanding of what they involved, and 50% had a poor understanding” Put this in perspective. “*Fair* understanding” (a step *up* from “poor understanding”) is this:

Interviewer: Do you know how it [ventilation] works to make you breathe?

Patient: No. . . .

Interviewer: What do you think it would be like to be on one?

Patient: Oh, I don’t want to be on one.

Interviewer: OK. Do you have any idea what it might be like to be one?

Patient: I don’t know.

Almost a quarter of the patients in this study already had an advance directive. One might hope that they would already know the relevant medical facts. But “[p]articipants who had previously written ADs did not have better knowledge of CPR or mechanical ventilation on any of these measures. In fact, those who had ADs were more likely to express the [false] view that ventilators directly kept the heart beating”

In sum, Fischer et al conclude that “patients left the conversations with serious misunderstandings about CPR and mechanical ventilation.” Did these patients perceive the unreliability of their knowledge and draw conclusions from it cautiously? No. Fischer et al comment that one “of the most disconcerting findings of this study was that patients expressed strong preferences about treatments that they did not understand.”

3. *Analyzing Information*

Even if patients receive information and understand it, they cannot make good decisions unless they analyze it acutely. Here too the evidence is discouraging. Bioethicists have little troubled to understand how people make medical decisions. Dan Brock states a measured and moderate version of the standard assumptions. The physician gives the patient “facts about the diagnosis and about the prognoses without treatment and with alternative treatments.” The patient provides “the values—his or her own conception of the good—with which to evaluate these alternatives” and selects “the one that is best for himself or herself.”¹¹

This sounds straightforward enough, but the reality is hopelessly different, as decades of psychological research have richly

11. Dan W. Brock, *The Ideal of Shared Decision Making Between Physicians and Patients*, 1 Kennedy Institute of Ethics J 28, 28 (1991).

shown. First, Brock's formulation assumes patients have "values" to supply, have beliefs that are coherent and considered enough that patients can deduce decisions from them. But people have better things to do than devising abstract principles for dreadful problems they hope will never arise. This is bad enough, yet the problem goes much deeper. For most of us much of the time, we find out what we value by observing and then justifying our choices. It is hardly too much to say that our "values" are the explanations we give for our decisions, not the source of them. So, Hibbard et al observe, much "research shows that preferences are remarkably labile and sensitive to the way a choice is described or framed."¹² This suggests that people "may not have existing preferences or beliefs about self-interest, but, rather, construct them in the process of deciding. . . . This new conception applies particularly to choices among options that are important, complex, and unfamiliar, like those consumers face in the current health care environment." As Richard Russo put it in my favorite academic novel (*Straight Man*), "The truth is, we never know for sure about ourselves [O]nly after we've done a thing do we know what we'll do Which is why we have spouses and children and parents and colleagues and friends, because someone has to know us better than we know ourselves."

Second, the canonical view of bioethics not only assumes that people have reliable values to apply; it assumes that they reason effectively about how to promote those values. However, a substantial literature now catalogs the ways that human beings misperceive reality and employ short cuts and rules of thumb which may work well in familiar situations but which systematically malfunction in less familiar ones. Professor Sage summarizes some of that literature:

[P]eople make striking and predictable errors when evaluating risks and either accepting, rejecting, or taking action to reduce them. These "cognitive biases" can be divided into "framing errors," which lead people to ignore actual probabilities and overestimate the likelihood of events that are familiar or salient, and "valuation errors," which induce people to overpay to avoid small, near-certain losses or lock in small, near-certain gains, to live with significant risks that they mistakenly believe they can control, or to insist on eliminating minuscule risks of especially dreaded events.¹³

Thus, for example, people

12. Judith H. Hibbard et al, *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*, 75 *Milbank Quarterly* 395, 402 (1997).

13. William M. Sage, *Accountability Through Information: What the Health Care Industry Can Learn from Securities Regulation* 12 (Milbank Memorial Fund, 2000).

consistently underestimate personal risk for hazards in certain situations: when the hazard is one with which individuals have had little personal experience; when hazards are perceived as low in probability; or when hazards are judged to be controllable by personal action. These types of hazards may include the potential for catastrophic illness, serious injury, or even less serious morbidities. This optimism bias in comparative risk judgments is robust and widespread.¹⁴

The literature on how people generally and patients particularly make decisions is so complex that it can hardly be summarized here. To provide a better sense of the evidence, I will sketch one of the many problems in making medical decisions that bioethicists virtually ignore. Decisions require us to predict how we will feel about future states. And how well do we predict our own preferences? In brief, we struggle ineptly to predict our own tastes, behavior, and emotions even over short periods and under familiar circumstances. We make systematic mistakes in anticipating what we will enjoy. We regularly “miswant.”¹⁵

This seems horribly counter-intuitive. But hearken to a—quite incomplete—list of errors we make in forecasting our feelings: People mispredict what poster they will like,¹⁶ how intensely they will relish yogurt,¹⁷ which snacks they will prefer over the next three weeks,¹⁸ how environmental changes will affect their well-being,¹⁹ how attached they will become to a free coffee mug,²⁰ how distressed they will be on receiving the results of tests for HIV²¹ and for Huntington’s disease,²² whether they will be happier living in Michigan or California,²³ how greatly they will enjoy a bicycle trip,²⁴

14. Judith H. Hibbard et al, *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*, 75 *Milbank Quarterly* 395, 401 (1997).

15. Daniel T. Gilbert & Timothy D. Wilson, *Miswanting: Some Problems in the Forecasting of Future Affective States*, in Joseph P. Forgas, ed, *Feeling and Thinking: The Role of Affect in Social Cognition* 178-79 (Cambridge U Press, 2000).

16. Charles H. Griffith, III, et al, *Knowledge and Experience with Alzheimer’s Disease*, 4 *Archives of Family Medicine* 780 (1995).

17. Daniel Kahneman & Jackie Snell, *Predicting a Changing Taste: Do People Know What They Will Like?*, 5 *J Behavioral Decision Making* 187 (1992).

18. Itamar Simonson, *The Effect of Purchase Quantity and Timing on Variety-Seeking Behavior*, 27 *J Marketing Research* 150 (1990).

19. George Loewenstein & Shane Frederick, *Predicting Reactions to Environmental Change*, in Max H. Bazerman et al, eds, *Environment, Ethics, and Behavior* (New Lexington Press, 1997).

20. George Loewenstein & Daniel Adler, *A Bias in the Prediction of Tastes*, 105 *Economic J* 929 (1995).

21. Elaine M. Sieff et al, *Anticipated Versus Actual Reaction to HIV Test Results*, 112 *American J Psychology* 297 (1999).

22. Sandy Wiggins et al, *The Psychological Consequences of Predictive Testing for Huntington’s Disease*, 327 *New England J Medicine* 1401 (1992).

23. David Schkade & Daniel Kahneman, *Does Living in California Make*

how joyful Bill Clinton's election would make them,²⁵ how gratified they will be to ace a test,²⁶ how painfully criticism will wound them,²⁷ how distraught they will be if their team loses,²⁸ how agonizing a visit to the dentist and other tormentors will be,²⁹ and, well, I could go on in this vein for some time.

We not only mispredict our emotions; we mispredict our behavior.

People go on dates planning to refrain from having sex, engage in foreplay with the expectation of using a condom at the next stage, and initiate sex with the plan to "interrupt" prior to the critical moment. As Gold found in interviews with gay men about their attempts to practice safe sex, however, such resolutions often break down in the "heat of the moment."³⁰

Profligacy is as unpredictable as passion: "[L]arge numbers of credit card users expect to maintain a zero credit balance but fail to do so . . ." ³¹ We can't even anticipate how much we will buy at the grocery store.³²

Worse, pondering choices does not always improve predictions. Some of the people researchers instructed to pick a poster "were asked to think about why they liked or disliked each poster ('deep thinkers') and others were not ('shallow thinkers')." Perversely, "the deep thinkers were the least satisfied."³³ And people asked "to predict how they would feel about the experience [of eating yogurt] over time [eight weeks] . . . expected to like it less over time but in fact liked it more . . ." But "[t]he most striking finding . . . was the

People Happy? A Focusing Illusion in Judgments of Life Satisfaction, 9 *Psychological Science* 340 (1998). Living in California doesn't make you happier than living in Michigan. Sometimes I wonder about this one.

24. Terence R. Mitchell et al, *Temporal Adjustments in the Evaluation of Events: The "Rosy View,"* 33 *J Experimental Social Psychology* 421 (1997).

25. Daniel T. Gilbert et al, *The Trouble With Vronsky: Impact Bias in the Forecasting of Future Affective States*, in L. F. Barrett & P. Salovey eds, *The Wisdom in Feeling: Psychological Processes in Emotional Intelligence* 114, 119-20 (2002).

26. Ibid at 120.

27. Daniel T. Gilbert et al, *Immune Neglect: A Source of Durability Bias in Affective Forecasting*, 75 *J Personality & Social Psychology* 617 (1998).

28. Timothy D. Wilson et al, *Focalism: A Source of Durability Bias in Affective Forecasting*, 78 *J Personality & Social Psychology* 349 (2000).

29. George Loewenstein & David Schkade, *Wouldn't It Be Nice? Predicting Future Feelings*, in Daniel Kahneman et al, eds, *Well-Being: The Foundations of Hedonic Psychology* 91 (Russell Sage Foundation, 1999).

30. Ibid at 93.

31. Ibid at 94.

32. Daniel T. Gilbert & Timothy D. Wilson, *Miswanting: Some Problems in the Forecasting of Future Affective States*, in Joseph P. Forgas, ed, *Feeling and Thinking: The Role of Affect in Social Cognition* 178 (Cambridge U Press, 2000).

33. Ibid at 183.

near-zero correlation between individual subjects' anticipated and actual reactions to the experience. Subjects' feelings *did* change substantially over time, but they had little idea, at the outset, about how they would change."³⁴

I have been describing failures to anticipate one's responses to events. These are partly failures to anticipate *which* reactions one will have. More commonly, they are failures to anticipate the *intensity* and the *duration* of one's reactions. These failures of anticipation have a common tendency—to over-estimate the intensity and duration of emotions. Your pleasure at the victory of your candidate on Tuesday is neither so profound nor so enduring as you expected on Monday. Indeed, "[t]he most prevalent error found in research on affective forecasting is the impact bias, whereby people overestimate the impact of future events on their emotional reactions."³⁵

I have taken pains to describe one element of human reasoning in order to provide a better feel for my larger argument—that people reason in ways that bedevil the work of making medical decisions. But the bioethical view of human decisions is exceptionally naive. It is this naive view that makes possible much bioethical thinking. It allows bioethicists to believe that patients will make good decisions if they are given information about their choice of treatments, that people can anticipate their situation and preferences well enough to write useful living wills, that people reason so reliably that family members can replicate their decisions when patients are incompetent, and that we all can be made sagacious purchasers of medical insurance plans and medical treatments. And so we are in endless error hurled.

4. *Closing Thoughts on Informed Consent*

Can informed consent be made to do better? Probably, but not much. We've been trying hard for decades. Even determined and lavish efforts in favorable circumstances regularly fail. They fail because teaching and learning are much harder than bioethicists think. (Are their bluebooks really so much better than mine?) Nor is the problem merely local: Peter Schuck observes that similar problems

appear in Canada, Europe, and Japan—countries whose organization of health care, political-regulatory structures, and professional culture and practices differ from ours in many

34. George Loewenstein & David Schkade, *Wouldn't It Be Nice? Predicting Future Feelings*, in Daniel Kahneman et al, eds, *Well-Being: The Foundations of Hedonic Psychology* 88 (Russell Sage Foundation, 1999). Ice-cream eaters, on the other hand, accurately predicted that they would like it less over the eight weeks.

35. Timothy D. Wilson & Daniel T. Gilbert, *Affective Forecasting*, 35 *Advances in Experimental Social Psychology* 345, 353 (2003).

fundamental respects. The fact that similar discursive patterns are universal . . . strongly implies that these patterns are so deeply rooted in the psychology and structure of a physician-patient relationship as to be largely immune to change through legal doctrine or other exogenous factors.³⁶

The evidence about informed consent is now several decades old. It is mountainous. It is damning. When failure is the norm, it is time to ask whether there are ineradicable reasons for the failure and time to go back to basics.

B. *Living Wills*

[An] exception to the doctrine that individuals are the best judges of their own interest, is when an individual attempts to decide irrevocably now what will be best for his interest at some future and distant time. The presumption in favor of individual judgement is only legitimate, where the judgment is grounded on actual, and especially on present, personal experience; not where it is formed antecedently to experience, and not suffered to be reversed even after experience has condemned it.

John Stuart Mill
Principles of Political Economy

Another prominent item in the bioethics agenda has been the living will. Living wills have now been investigated at length and in detail.³⁷ They have failed and cannot be rescued: They seem not to affect the care patients receive. Even if they did, they would almost surely not increase the likelihood that patients would receive the care they wanted. This is not only what the evidence shows, it is what reason suggests. First, it is exceptionally difficult for patients to acquire information about the illnesses from which they might be suffering when incompetent, the treatments that might be available, and the consequences of the maladies and treatments. Second, patients can rarely survey all this information and then reach decisions about the treatment they would want that actually match the decisions they would have made if competent. Third, attempts to put preferences of the relevant kinds into accurate and useful words have persistently failed. Fourth, getting the living will to the right place has been harder than first seemed likely. Fifth, the living will must be relevant, read, and understood, requirements which are regularly frustrated. Sixth, the joker in the deck is that

36. Peter H. Schuck, *Rethinking Informed Consent*, 103 Yale L J 899 (1994).

37. In this paragraph I draw on Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, Hastings Center Report 30 (March/April 2004).

patients stubbornly resist writing living wills.

Consider just one of the steps that would have to be taken to salvage the living will—doctors would have to give patients enough information for them to make good prospective decisions. Communication between doctors and patients about end-of-life decisions has been the subject of decades-long effort. And how, after all those years of adjuration does that communication actually occur? One spectacularly ambitious project—the SUPPORT study—investigated over nine thousand gravely ill patients in five prominent teaching hospitals over four years.³⁸ Doctors were given reports on patients' prognoses and were told patients' feelings about CPR, treating pain, receiving information, and advance directives. Specially trained nurses promoted communication among patients, their surrogates, and their doctors. Succinctly, SUPPORT worked “no significant change in the timing of DNR orders, in physician-patient agreement about DNR orders, in the number of undesirable days [patients experienced], in the prevalence of pain, or in the resources consumed.” The experiment did not alter patients' preferences about DNR orders, their communication with doctors, or their satisfaction with their care. Only 15% of the doctors discussed the information they received with patients (or surrogates). In sum, despite a prodigiously elaborate and costly program, almost nothing budged.

Let me give flesh to the statistical skeleton with a prominent doctor's horrifying description in a prominent magazine of how he “discussed” these issues with his patient:

“Most people say that if they reach a point in the illness when their brain is impaired, and there is no likelihood of improving their quality of life, then nothing should be done to keep them artificially alive, through machines like respirators. It's essential, Maxine, that I know what you want done if we reach that point.”

“I—I don't think I would want that,” she said haltingly.

“You mean that you would want only comfort measures to alleviate pain, and nothing done to prolong your life, like a respirator or cardiac resuscitation?”

“Yes, I think so,” Maxine whispered.

38. SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591 (1995).

I nodded. This was her “end-of-life directive.” I would put it in writing in her medical chart.³⁹

This is how people decide to die? This is how a well-known physician didactically describes his own methods in a popular magazine? First, Groopman virtually strong-arms his patient into accepting the course he prefers. He is surely making a recommendation, but he never warns Maxine that that is what he is doing. He cloaks his recommendation in the ratification of “most people,” but do “most people” say any such thing? Groopman’s choice of words is tendentious. He speaks, for example, of being “artificially” alive. What does that mean? Is there such a category?

What is more, when Maxine seems to be acquiescing, Groopman does not trouble to find out whether she understands his proposal. Worse, he closes the sale briskly by transmuting her tentative murmurs into final affirmations. Her first reaction to his proposal actually seems to be to contradict it. (All depends on what you think “that” refers to; grammatically, it could refer to refusing treatment, which she doesn’t think she wants.) In any event, she speaks “haltingly,” and she says only that she doesn’t think she wants “that.” Her second reaction is again phrased tentatively: she “whispers” that she *thinks* she agrees with him, which implies that she is not sure. But presto—behold the “end-of-life directive.”

Second, observe how radically vague this “end-of-life directive” is. It postulates a point when patients’ brains are impaired and “there is no likelihood of improving their quality of life.” How impaired? Many things impair people’s brains without their wanting to die. Only egregious impairment ordinarily provokes that. But even “egregious impairment” gives scant guidance. Another crucial phrase in this living will is “no likelihood of improving” quality of life. Really? *No* likelihood? *No* chance? Physicians hate to say anything so absolute. But if not “no” likelihood, then what likelihood? And what treatments is she forgoing? Groopman speaks of “machines like respirators.” What machine is like a respirator? Is Maxine objecting to being kept alive or to being kept alive by machines?

Third, how much did Maxine understand about what was going on? The “directive’s” words are, as I just argued, wretchedly vague. If Maxine is like most patients, she does not know what “a respirator or cardiac resuscitation” might mean. Most appalling of all, Maxine evidently had no idea she had just issued a binding “end-of-life directive.”

After all these years of advocating advance directives, is this where we are? If Maxine dies because treatment is withheld, it will be in the name of autonomy, and no questions will be asked. But

39. Jerome Groopman, *Dying Words*, New Yorker, October 28, 2002, at 62, 63.

what is really going on here? Is all this just medical imperialism in new guise? Has Groopman heard so often that doctors overtreat patients at the end of life that he is determined it will not happen to his patients? Does Groopman actually believe that genuinely autonomous decisions are so easily come by? If it does nothing else, the story of Maxine should drive us to confront clearly and honestly what autonomy has come to mean and what it can realistically mean.

But imagine a patient less vulnerable than poor Maxine and a physician more helpful than (adjectives fail me) Groopman. Imagine a healthy patient with time and resources to devote to writing a living will. And imagine that the patient had unfettered access to a communicative physician. How well would that patient's living will actually anticipate and communicate the decisions the patient would have made if competent?

The problem, of course, lies not just in giving the authors of living wills accurate information and useful assistance. It also lies in patients' analysis of their choices and preferences. Recall now our discussion of the problems people have predicting their reactions to events and anticipating what will make them happy. If people mispredict their reaction to homely, common experiences, they will *a fortiori* misanticipate their reaction to the unfamiliar issues raised by living wills, especially to hypothetical choices and disturbing circumstances. Thomas Mann saw the problem:

The pity the well person felt for the sick—a pity that almost amounted to awe, because the well person could not imagine how he himself could possibly bear such suffering—was very greatly exaggerated. . . . It was, in fact, the result of an error in thinking, a sort of hallucination; in that the well man attributed to the sick his own emotional equipment, and imagined that the sick man was, as it were, a well man who had to bear the agonies of the sick one—than which nothing was further from the truth. For the sick man was—precisely that, a sick man: with the nature and modified reactions of his state.⁴⁰

More particularly, people regularly fail to anticipate how illness and disability will affect them. Some of the most systematic evidence of this failure comes from comparisons between the way patients evaluate their lives and the way others evaluate those lives. Discrepancies in these evaluations are chronic. For example, “the general public estimates the health related quality of life (HRQoL) of dialysis at the value of 0.39 (on a scale where 0 represents death and 1 represents perfect health), whereas dialysis patients estimate their HRQoL at 0.56 Patients without colostomies estimate the

40. Thomas Mann, *The Magic Mountain* 451 (H.T. Lowe-Porter trans., 1968).

HRQoL of living with a colostomy at 0.80, while patients with colostomies rate their own HRQoL at 0.92.”⁴¹ Similarly, “[i]n one study of 126 elderly outpatients with five common chronic diseases . . . Pearlman and Uhlmann found that patients generally rated their quality of life to be slightly worse than ‘good, no major complaints,’ but their physicians rated their quality of life as significantly worse”⁴² The moral, of course, is that if people cannot even perceive how patients they know are currently handling illness, they cannot foresee how they themselves might someday react to it.

In sum, the evidence about the living will closely resembles the evidence about informed consent. In both cases, there is much reason to doubt that patients receive enough sound information to make good decisions, that they satisfactorily understand the information they do receive, or that they analyze it with the acuity they themselves would wish. And in both cases, there is little reason to believe that any of these deficiencies can be adequately remedied.

C. Consumer-Directed Health Care

The whole thing reminds me of the uncomfortable feeling I experienced when I first sought out investment advice. . . . [F]inancial advisers, well intentioned and competent as they might have been, were all favoring their own financial instruments. I concluded that I had . . . to take the high-level management of my investments into my own hands. Similarly, . . . that's the only viable choice any patient has. If you look after your investments, I think you should look after your life as well. Investigate things, come to your own conclusions, don't take any one recommendation as gospel.

Andy Grove

Taking on Prostate Cancer

The *dernier cri* in the ethics of health-care finance is “patient-directed health care.” The AMA Council on Ethical and Judicial Affairs proclaims that “patients have a responsibility to learn as much as they can about their choices of plans, including the exact nature of the different benefits packages and their limitations. Patients have a responsibility to make sure they know and

41. Peter A. Ubel et al, *Whose Quality of Life? A Commentary Exploring Discrepancies Between Health State Evaluations of Patients and the General Public*, 12 *Quality of Life Research* 599, 599 (Kluwer Academic Publishers, 2003) (footnotes omitted).

42. George Loewenstein & David Schkade, *Wouldn't It Be Nice? Predicting Future Feelings*, in Daniel Kahneman et al, eds, *Well-Being: The Foundations of Hedonic Psychology* 90, 92 (Russell Sage Foundation, 1999).

understand the terms of their own health care plan.”⁴³ The claim is that when people meet those responsibilities they will buy medical insurance, subscribe to health-care plans, and purchase medical goods and services so astutely that they will get what they want at tolerable prices.

Perhaps it is too soon to evaluate this gloriously optimistic proposal. However, minatory evidence is mounting rapidly. Here, as elsewhere in bioethics, the seeds of failure lie first in the difficulty of providing patients useful information. Only rarely do people comprehend even crudely “the information infrastructure on which the theory of competitive market and the theory of managed care rest.” Some information about prices is even “jealously guarded proprietary information.” Worse, information about “the quality of care is generally unavailable or not trustworthy. Not even the infection or complication rates experienced in hospitals are publicly known. Such information on quality as is made available in the media or on Web sites typically consists of mysteriously weighted aggregate indexes that obscure the detailed information patients would need in a competitive market.”⁴⁴

But, as usual, there are reasons useful information is not forthcoming. Not least, it is wickedly hard to put information in terms consumers can use. And as usual, honorable efforts have been made to tell patients what they need to know to make good purchases. For example, experiments with HMO “report cards” have sought to employ “several performance measures and plan characteristics to compare multiple plans.” Thus “the Minnesota Health Data Institute distributed a 16-page, statewide report card that featured comparison tables and color-coded graphs of consumer satisfaction within categories of health plans and compared 38 plans based on 20 performance measures.” However, “less than half of those seeing the report thought it was helpful for deciding on a plan. Consumers found the report cards cumbersome, complex, and detailed.”⁴⁵

Even precise and complete information is useless if it is misunderstood. People read information through the prism of their own knowledge. And their knowledge about the market for health care is sadly distorted. For example, 30% of those surveyed in one study “knew almost nothing about HMOs.” Of the remaining patients, “only 16 percent had adequate knowledge (scores of 76 percent or higher) to choose between traditional Medicare and an

43. Council on Ethical and Judicial Affairs, American Medical Association, *Ethical Issues in Managed Care*, 273 JAMA 330 (1995). How many physicians, much less patients, meet this standard?

44. Uwe E. Reinhardt, *Can Efficiency in Health Care Be Left to the Market?*, 26 J Health Politics, Policy & Law 967, 986–87 (2001).

45. Judith H. Hibbard et al, *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*, 75 Milbank Quarterly 395, 396–98 (1997).

HMO. More than 41 percent scored in the 'inadequate' range (scores of 50 percent or less)" Only a third of those remaining patients "understood how physicians are paid under a fee-for-service system, and only about 40-50 percent understood that HMO doctors may be paid on a capitation basis." In short, few "beneficiaries are well informed about their choices. Even those who use multiple information sources to learn about health plans often have less-than-adequate knowledge."⁴⁶

All this means, at best, that consumers generally lack, as Professor Sage writes, "baseline information that could provide context for required disclosure. Therefore, health care consumers can easily misinterpret even accurate data." In one study, for example, "potential enrollees regarded report card data showing high hospitalization rates of health plan enrollees for pneumonia as showing leniency in approving inpatient treatment rather than demonstrating failure to administer vaccinations."⁴⁷

Decisions about buying medical care are enormously complex, and people's needs are enormously various. So people need mountains of information. But the more information you have, the harder it is to comprehend, remember, and analyze. Hibbard et al observe that "a large body of empirical work" suggests "that the integration of different types of information and values into a decision is a very difficult cognitive process." Partly, "people can process and use only a limited number of variables." This is true even of experts. Thus, a study of handicappers for horse races found that as "more information was used, confidence in the decisions went up. However, predictive ability was as good with 5 variables as with 10, 20, or 40. . . . Further, the reliability of the choices decreased as more information was made available. That is, when individuals had more information, their ability to use it 'consistently' declined."⁴⁸ If experts falter, what hope for you and me?

Even if consumers are offered the information the "contract" view of regulation suggests they need, they will reject much of it. For example, not only are patients ill-informed about physician payment in managed care, "only about half say they want to know such details."⁴⁹ Even when people say they want information, they routinely ignore it. For instance, "most consumers who have comparative plan performance information do not use that information in making their enrollment decisions, although most

46. Judith H. Hibbard et al, *Can Medicare Beneficiaries Make Informed Choices?*, 17 *Health Affairs* 181 (1998).

47. William M. Sage, *Accountability Through Information: What the Health Care Industry Can Learn from Securities Regulation* (Milbank Memorial Fund, 2000).

48. Judith H. Hibbard et al, *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*, 75 *Milbank Q* 395 (1997).

49. Sage, *Accountability* at 36 (cited in note 47).

say that plan quality is very important to them.”⁵⁰

Patients have other problems in bringing themselves to consult systematic information. For one thing, such information is generally “sterile compared with people’s emotional investment in health care.” The measures used in systematic information “tend to emphasize disease states and the processes that prevent or treat them,” but “consumers in focus groups show limited interest in or ability to interpret technical information divorced from their individual circumstances. Instead, ordinary people seem to prefer subjective, relational information from ‘people like them’”⁵¹ Yet what is more notoriously misleading than the anecdote?

Dr. Johnson famously called a second marriage the triumph of hope over experience. What can we call consumer-directed health care? After our travail with informed consent, after our frustration with living wills, why would anyone think that the problems of explanation, comprehension, and analysis will vanish when people are asked to purchase health insurance, health plans, and health care?

III. MANDATORY DISCLOSURE

The human understanding is not a dry light, but is infused by desire and emotion, which give rise to ‘wishful science’. For man prefers to believe what he wants to be true. He therefore rejects difficulties, being impatient of inquiry; sober things, because they restrict his hope; deeper parts of Nature, because of his superstition; the light of experience, because of his arrogance and pride, lest his mind should seem to concern itself with things mean and transitory; things that are strange and contrary to all expectation, because of common opinion.

Francis Bacon
Novum Organum

The evidence we have surveyed repeatedly demonstrates that equipping people to make good decisions about complex, foreign, and frightening issues is challenging far beyond the facile assumptions of the bioethical agenda. It is therefore critical that, when that agenda has been promoted through law, one device has been overwhelmingly called on—mandatory disclosure. The examples are familiar. Doctors must tell patients what they need to know to make medical decisions. Researchers must tell patients about the risks of participating in experiments. Hospitals must tell patients about advance directives. Doctors and hospitals must tell patients

50. Russell Korobkin, *The Efficiency of Managed Care “Patient Protection” Laws: Incomplete Contracts, Bounded Rationality, and Market Failure*, 85 *Cornell L Rev* 1, 70 (1999).

51. Sage, *Accountability* at 35-36 (cited in note 47).

about their privacy regimes. “Virtually every bill . . . to regulate managed care devotes major portions to information disclosure and dissemination.”⁵² The list goes on; I will not.

Mandatory disclosure is a hoary regulatory technique. And why not, since it ought to work? Don’t people making decisions need information, want it, and use it? Doesn’t an irresistible array of arguments justify disclosure requirements? The *moral* rationale is that disclosure liberates people from the servitude ignorance creates. The *prophylaxis* rationale assumes that predators can be discouraged if they must warn their prey. The *market* rationale holds that the production and allocation of goods is best regulated through markets and that markets work best when purchasers know most. And the *welfare* rationale supposes that we enhance people’s well-being giving them the information they need to organize their lives.

Nevertheless, as we have seen, disclosure requirements in health law seem not to work as intended. Can they be fixed? Well, consider the many other areas of law that deploy them. Are people buying worthless stocks? Securities laws say, “Disclose!” Are people borrowing money at usurious rates? Consumer protection laws say, “Disclose!” Are people injured by things they buy? Products-liability law says, “Disclose!” Are police bullying criminal suspects into waiving their rights? *Miranda* says, “Disclose!” Are people signing disadvantageous marital agreements? Family law says to the couple, “Disclose!”

Do these disclosure requirements work? Their goal is to improve decisions. The baseline for evaluation, then, is the quality of the decisions people would make were there no disclosure laws. Crudely defined, success would mean improving decisions enough to justify the costs of the disclosure requirement to the government, disclosers, and recipients.

This standard of assessment is heroically challenging to apply. However, I doubt it is often met. If disclosure requirements prosper anywhere, it should be in securities markets, since they are dominated by institutions which have reasons and resources to use the information corporations disclose. But even there, scholars cannot agree that corporations would disclose less were there no securities laws (since corporations have economic incentives to disclose information to investors) or that the disclosures that are made improve investors’ decisions.

Most other disclosure regimes look worse. For example, *Miranda* has “little or no effect on a suspect’s propensity to talk Next to the warning label on cigarette packs, *Miranda* is the most widely ignored piece of official advice in our society.’ . . . Not only has *Miranda* largely failed to achieve its stated and implicit goals,

52. William M. Sage, *Regulating Through Information: Disclosure Laws and American Health Care*, 99 Columbia L Rev 1701, 1707-08 (1999).

but police have transformed *Miranda* into a tool of law enforcement”⁵³ Another example. While the evidence of failure is hardly uniform, “the efforts of researchers to prove by scientific means that on-product warnings are indeed effective to modify safety-related behavior in actual or simulated real-world applications have generally yielded disappointing results.”⁵⁴

This hardly bodes well for mandatory disclosures in medicine. But perhaps we can understand more if we ask why disclosure requirements work badly. Principally, disclosure succeeds only if *many* onerous conditions are all met. Let us briskly survey eight of them.

First, information must actually be provided. However, disclosers often have reasons to withhold it, if only because disclosures cost money and can compromise disclosers’ interests. Furthermore, disclosure requirements are hard to enforce: They usually affect so many transactions that the law cannot supervise them well administratively, and people from whom information is withheld rarely are injured enough to make suits economically sensible.

Second, the information disclosed must be the right information—relevant, true, clear, complete. However, even willing disclosers often do not know what to disclose and how best to disclose it. For example, some safety warnings apparently make people less cautious, not more. Cigarette warnings seem to have helped convince Americans that the dangers of smoking are *greater* than they actually are. This might be all to the good. However, the young start smoking partly because they over-estimate people’s ability to stop. This seems to call for another round of package disclosures. Yet you can’t tell people *everything*, because that drowns them in more information than they can cope with.

Third, the audience must receive—and thus must perceive—the information. But often the information is, and even must be, inconspicuous. Furthermore, 40 to 44 million Americans, or roughly one quarter of the US population, are functionally illiterate, another 50 million are marginally literate, and many of the rest have trouble comprehending even modestly complex verbal and numerical data.

Fourth, recipients must attend to the information they perceive. But recipients commonly fail to recognize the relevance and significance of information or think they already know all they need to. Thus, they are easily convinced that the trouble of grappling with information will not be repaid. So how do you seize someone’s attention? One “of the most consistent findings in the literature . . .

53. Richard A. Leo, *Questioning the Relevance of Miranda in the Twenty-First Century*, 99 Mich L Rev 1000, 1013, 1021 (2001).

54. Hildy Bowbeer & David S. Killoran, *Liriano v. Hobart Corp.: Obvious Dangers, The Duty to Warn of Safer Alternatives, and the Heeding Presumption*, 65 Brooklyn L Rev 717, 757 (1999).

is that a consumer's responsiveness to warnings is strongly affected by perceived hazardousness." Those perceptions are influenced by too much, including "the overall appearance of a product, . . . perceived controllability of the hazard and its harmful consequences, . . . a person's ability to imagine various ways in which an injury might occur while using a product, . . . familiarity with the product, . . . level of education or a person's abilities of processing information, . . . and the presence, . . . salience, . . . and content of warnings." Alas and of course, "[m]ost of these factors are difficult to influence."⁵⁵

Fifth, people must understand the information. This requires the kind of analytic effort most of us resist. And rightly resist. As Whitehead wonderfully said, "It is a profoundly erroneous truism, repeated by all copy-books and by eminent people when they are making speeches, that we should cultivate the habit of thinking about what we are doing. . . . Civilization advances by extending the number of important operations which we can perform without thinking about them. Operations of thought are like cavalry charges in a battle—they are strictly limited in number, they require fresh horses, and must only be made at decisive moments."⁵⁶ But even when we reluctantly recognize that the cavalry should charge, we hate to bring out the fresh horses.

Sixth, recipients must believe what they are told. But people scout information that does not fit their view of the world. Furthermore, recipients often have reasons (good and bad) to fear that disclosers are shaping information to serve their own interests and not the recipients'. (How many suspects believe what the police tell them? How many should?) Such attitudes make recipients all too prone to spurn even true and good information.

Seventh, people must decide to use the information. But people regularly resist incorporating new information into decisions, if only because that demands still more labor. People must therefore be convinced that their effort will be repaid. Sometimes it is, sometimes it isn't. You can't know until you've tried. You can't know if trying is worth trying.

Eighth, people must use the information intelligently. The woeful rarity of this even where you would expect it most is suggested by shelves of books with titles like *Why Smart People Make Big Money Mistakes and How to Correct Them*. Even experienced investors overvalue their own judgment, are sooner swayed by vivid than dry data, delusively imagine that new evidence confirms their earlier opinions, and are addled by the buzzing swarm of systematic faults in reasoning that befuddle us

55. Monica Trommelen, *Effectiveness of Explicit Warnings*, 25 *Safety Science* 79 (1997).

56. Alfred North Whitehead, *An Introduction to Mathematics* 41-42 (Oxford U Press, 1948).

all. And so, for a small but chastening example, “[d]uring the Internet frenzy, firms that announced that they were changing their name to include ‘dot.com’ experienced abnormal returns, regardless of whether the announcement coincided with a change in business plan.”⁵⁷ To put this crucial point differently, people’s decisions often do not change, much less improve, with more information.

But why do lawmakers so often choose disclosure requirements when evidence for their success is (at best) so elusive and (at worst) so damning? One answer is that the structure of most law-making does little to encourage assessments of disclosure rules. Those rules are commonly inspired by indignation over genuine problems, indignation inflamed by anecdote.⁵⁸ Attention is directed to what is wrong and the imperative of change, not to the effectiveness of the law’s means. Anyway, it seems obvious that disclosure works, and there is no easy way to test its effectiveness in advance. And law is made by just the people—the well-educated and well-situated—best able to take advantage of disclosures and most convinced they want them.

Furthermore, disclosure may be the only kind of regulation available to the law-maker. For instance, courts can create a cause of action against doctors who do not disclose information to patients, but courts cannot establish an administrative apparatus to supervise disclosure or medical treatment. And delightfully, disclosure requirements cost lawmakers a pittance, since they shift the costs of regulation to the regulated entities. For example, the Patient Self-Determination Act added farthings to the federal budget, but it cost hospitals over \$100,000,000 just to set up compliance programs.⁵⁹ Finally, once disclosure rules have been implemented, courts have no resources for or—it must be said—interest in reviewing their effectiveness, and Congress has moved on to other issues.

At this point, I want to emphasize a feature of medical decisions that crucially affects *all* attempts to create a world in which patients make good use of medical disclosures. Most writing on patients’ autonomy—judicial and academic—assumes patients yearn to make medical decisions but are thwarted by medical imperialism. How true is this? The studies reach a surprising and surprisingly consistent conclusion: While many patients say they want to make decisions, a very substantial number of patients say they do not. Two studies give a keener sense of the research.

57. Stephen J. Choi & A.C. Pritchard, *Behavioral Economics and the SEC*, 56 *Stanford L Rev* 1, 14 (2003).

58. For a good description of a doleful example, see David A. Hyman, *Drive-Through Deliveries: Is “Consumer Protection” Just What the Doctor Ordered?*, 78 *North Carolina L Rev* 5 (1999).

59. Jeremy Sugarman et al, *The Cost of Ethics Legislation: A Look at the Patient Self-Determination Act*, 3 *Kennedy Institute of Ethics J* 387 (1993).

Ende and his colleagues⁶⁰ found that patients do indeed want information. Thus, “the mean score for information seeking was [on a 0-to-100 scale] 79.5 ± 11.5 .” But patients were considerably less interested in making decisions: “On a scale where 0 indicates a very low and 100 indicates a very high preference for decision making, and 50 indicates a neutral attitude, the mean score for the study population was 33.2 ± 12.6 .” Furthermore, “as patients were asked to consider increasingly severe illnesses, their desires to make decisions themselves declined.”

Similarly, William Strull et al found that patients little yearned to make their own decisions: “[N]early half (47%) of patients preferred that the clinician make the therapeutic decisions ‘using all that is known about the medicines’ but without the patient’s participation” A third “preferred that the clinician make the decision ‘but strongly consider the patient’s opinion.’ Only 19% of the patients stated they wish to share equally with the clinician in making the decision, and 3% wished to make the decision themselves.” Interestingly enough, physicians *over-estimated* patients’ desire to make medical decisions: “In contrast to the patient preferences, in the large majority of cases (78%) clinicians believed that patients wanted to help make decisions. In only 22% of cases did the clinician think the patient wanted the clinician alone to decide.”⁶¹

The Ende and Strull studies exemplify many others which conclude that, while patients largely wish to be informed about their medical circumstances, substantial numbers of them do not want to make their own decisions, or perhaps even to participate in those decisions in any truly significant way. Furthermore, the older patients are and the sicker they get, the more they shun medical decisions. Rather, they are willing to defer to doctors or family members.⁶²

The sturdy, stalwart strength of this reluctance is suggested by a fascinating inquiry from Ende et al. They asked *doctors* how they would want decisions made should they have an upper-respiratory tract infection, hypertension, or a myocardial infarction, all “diseases that fall within the realm of their professional expertise.” Even doctors “preferred that their provider take the principal role as decision maker.” The differences in the reluctance of doctors and patients to make their own decisions “were small.” And when “physicians who actually were enrolled as patients were compared

60. Jack Ende et al, *Measuring Patients’ Desire for Autonomy: Decision Making and Information-Seeking Preferences Among Medical Patients*, 4 J General Internal Medicine 23 (1989).

61. William M. Strull et al, *Do Patients Want to Participate in Medical Decision Making?*, 252 JAMA 2990 (1984).

62. I survey this literature at tedious length in Chapter 2 of *The Practice of Autonomy: Patients, Doctors and Medical Decisions* (Oxford U Press, 1998).

with the regular patient population, in the setting of severe illness no significant difference was found.” Finally, like patients, doctors became less willing to make their own decisions as their illness worsened.⁶³

A similar pattern evidently appears in another kind of health decision—purchasing health care. This is specially important because “consumer-driven health care” is, as I said earlier, the latest incarnation of the hydra-headed autonomy monster. For example, when focus groups are shown the report cards that are intended to inform consumers, they “commonly respond that they find the information overwhelming and confusing and that they do not know how to use the lava flow of information to make a decision. Many say they prefer to have someone tell them which plan to choose.”⁶⁴

This kind of response horrifies autonomists, who believe that if only people are dosed with enough “education” they will be prepared and prompted to make their own decisions and want to do so. However, Hibbard et al conclude that “even with extensive and high-quality education programs, a significant portion of beneficiaries will not be able to use the information to make informed choices.” Among the reasons is that the “options are complex and require significant health care contextual information to understand them. Many beneficiaries will need one-on-one help to find their way to a satisfactory choice.”⁶⁵

The evidence I have surveyed powerfully suggests that the gulf between bioethical hopes for the autonomy principle and the actual consequences of bioethical policies is unbridged. But it must always be hard to show that the gulf is unbridgeable. I have adduced two kinds of evidence for that proposition. In earlier sections, I argued that the failure to bridge the gulf after decades of engineering suggests that the bridge simply cannot be built. In this section, I have argued that the failure to construct similar bridges in other regulatory areas gives us yet further reason to doubt that the bridge is feasible.

IV. PERESTROIKA?

Your education begins when what is called your education is over – when you . . . have begun yourselves to work upon the raw material for results which you do not see, cannot predict, and which may be long in coming – when you take the fact

63. Jack Ende et al, *Preferences for Autonomy When Patients Are Physicians*, 5 J General Internal Medicine 506 (1990). The physicians were significantly less anxious for information than the patients.

64. Judith H. Hibbard et al, *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*, 75 Milbank Quarterly 395, 398 (1997).

65. Judith H. Hibbard et al, *Can Medicare Beneficiaries Make Informed Choices?*, 17 Health Affairs 181, 192 (1998).

which life offers you for your appointed task. No man has earned the right to intellectual ambition until he has learned to lay his course by a star which he has never seen – to dig by the divining rod for springs which he may never reach. In saying this, I point to that which will make your study heroic. For I say to you in all sadness of conviction, that to think great thoughts you must be heroes as well as idealists.

Oliver Wendell Holmes
The Profession of the Law

At the heart of the bioethical agenda has been the effort to transfer decisions to patients and to equip patients to make them wisely. The law has been recruited to promote many such transfers, primarily through mandated disclosures. But in area after area, the bioethical agenda and the law implementing it seem to have importantly failed, and no plausible reform of that law looks significantly promising.

Grim as the evidence is, *no* amount of failure provokes bioethicists to wonder whether a specific proposal, the bioethical program, or the tools of bioethical regulation might be irredeemably flawed. Failure only drives them to add layer upon layer of Ptolemaic complexity. Were first-generation living wills laughably vague? Strive for completeness. Were second-generation living wills laughably complex? Solicit statements of “values.” Were third-generation living wills laughably opaque? Claim that they provoke conversations with physicians or families. Do physicians fail to talk with patients about care after incompetence? Educate them better. Do physicians fail to respond to education? Educate them some more, yea, unto seven times seventy. At some point, shouldn’t repeated failure lead you to ask why your program is not working and whether it can ever work?

As I have insisted to the point of ennui, in this essay I can only sample the evidence of failure. But if my sample is at all representative, bioethical programs, especially the law of bioethics, have failed so dramatically that bioethics should be fundamentally re-examined. What might that re-examination look like? Could it be profitable?

The most constrained response to bioethical failure might be to adjust the standards of bioethical success. We might, for example, decide that patients should not be asked to make their own decisions, but rather should be satisfied with what one might pejoratively call ill-informed consent. Another constrained response would be to conclude that specific parts of the bioethical program are so hopeless that they should be abandoned altogether, even while retaining the rest. For example, Angela Fagerlin and I have made a systematic case that there is so little prospect that living wills can ever work that they should be abandoned, but we argue that a more modest device—the durable power of attorney—should

be retained (since it can help resolve questions of authority to make decisions for incompetent patients, presents patients a task within their competence, and costs little).⁶⁶

Perhaps the most radical response to the failure of so many bioethical policies would be to acknowledge that there is no *a priori* reason there must be a field of bioethics. If useful things cannot be said about bioethical issues, why slog on? Less radically, if bioethics has little to contribute to the formulation of good policy, then it should be relegated to the work of theorizing until it has produced theories that intelligently guide policy.

There may be a middle course. Once we have shown—if indeed it can be shown—that the central bioethical enterprise of confiding decisions to patients in some strong sense is doomed, we can ask whether there are other issues about which helpful things *can* be said and done. We could do this *ad hoc*, but I would attempt a modestly more systematic approach.

I would start with the observation that bioethics' agenda largely comprises subjects bioethicists find intellectually interesting and ideologically agreeable. Bioethicists have offered patients what bioethicists think they want for themselves—autonomy and the ability to make medical decisions. Yet patients have in crucial ways rejected the bioethicists' gift. What, then, if bioethicists asked not what patients should want and instead asked what they do want? What would such a patient-centered bioethics look like?

A quick clarification. One could review and expand the empirical literature about what patients say they want. But such a simple picture of patients' preferences could not be dispositive. Patients need not understand their interests better than anyone else: Patients are likely to have only a poor idea of what they might seek from a bioethical agenda because they have never thought systematically about the subject. But asking what patients experience, what patients want, and what gives patients satisfaction may provide illuminating (and sobering) insights into what the bioethical agenda is and should be.

What principles might guide patients setting an agenda for bioethics? Patients presumably care naught about the intellectual fascination of issues. They care whether issues affect them, and they want to change the things that harm them. This suggests two criteria. First, bioethicists should concentrate on problems many patients encounter. Second, bioethicists should ask whether a problem lends itself to solution.

When I ask patients what they want from their physicians, I usually receive two answers—competence and (in the broadest possible sense) kindness. The former issue deals with a classic problem in professional ethics—what level of skill and effort do

66. Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, Hastings Center Report 30 (March/April 2004).

professionals owe clients? The latter issue deals with a classic problem in the relationship of professionals and client—what kinds of interactions should clients hope for from professionals they hire? Both issues raise questions about the virtues physicians should study and practice.

When we put these considerations together, a major bioethical topic like assisted suicide seems marginal because it affects so few people. On the other hand, bioethics might be led to a problem it has regrettably scanted:⁶⁷ “The undertreatment of pain in the United States is well-documented in scientific literature.” Studies “have demonstrated continued inadequacies in treatment (1) of those patient populations most likely to suffer from chronic and acute pain, including terminally ill patients, cancer patients, nursing home residents, elderly individuals, and chronic pain patients, and (2) in those medical environments where acute pain is routine, such as the emergency room, the post-operative unit, and the intensive care unit.”⁶⁸

For example, one large-scale “study of seriously ill hospitalized patients [the SUPPORT study] demonstrated a high prevalence of pain. Half of the patients in this study complained of pain and one-sixth reported extremely severe pain of any frequency or moderately severe pain occurring at least half of the time. Questioning suggested that pain was related to chronic conditions, as well as to the patients’ acute illnesses and their treatment.” This study “found clinically important levels of pain and dissatisfaction with pain control in all disease categories, including chronic obstructive pulmonary disease and congestive heart failure, diseases that have not been traditionally associated with pain.” While pain was virtually pervasive, some specialties failed more completely than others: “Surgeons’ patients reported increased levels of pain compared with patients of other specialists. . . . Compared with oncologists’ patients, patients of pulmonologists or intensivists were more dissatisfied with pain control.”⁶⁹ Even “five years after the

67. In what follows, I will suggest that bioethics has under-examined several areas. In each of these areas, one can find *some* writing. But the question is not whether some articles can be located; it is whether a topic has been given the attention it deserves and whether it has received little attention compared with other bioethical topics. Pain is a good example. Admirable efforts have been made to address the problem. (See Sandra H. Johnson, *Relieving Unnecessary, Treatable Pain for the Sake of Human Dignity*, 29 J L, Medicine & Ethics 11 (2001), for a discussion of some of them.) Nevertheless, those efforts are slight compared with the severity of the problem and the oceans of writing on other topics.

68. Amy J. Dilcher, *Damned If They Do, Damned If They Don't: The Need for a Comprehensive Public Policy to Address the Inadequate Management of Pain*, 13 Annals of Health Law 81, 83-84 (2004).

69. Norman A. Desbiens et al, *Pain and Satisfaction With Pain Control in Seriously Ill Hospitalized Adults: Findings From the SUPPORT Research Investigations*, 24 Critical Care Medicine 1953 (1996).

completion of patient enrollment in SUPPORT” it appears that “pain control persists as a major problem for hospitalized patients. These patients are still in pain many months after their hospitalization and experience pain and other symptoms even on their deathbeds.”⁷⁰

In short, the undertreatment of pain affects *far* more people than end-of-life issues like assisted suicide and even living wills. The problem not only afflicts horrifying proportions of dying patients, but millions of patients with undertreated chronic pain. And gratifying improvement can probably be made in ameliorating the problem: First, it is easier to change the behavior of physicians than patients. Second, we already are making progress.⁷¹

Or take another question of importance to most doctors and most patients: Even though an increasingly central fact about modern medical care is that it is delivered bureaucratically, bioethics has had little to say about the patient and doctor in the machine. Today, many of the ethical problems doctors (especially young doctors) confront raise issues of the ethical obligations of people operating in organizations, not just issues of traditional medical ethics.⁷² And what are the ethical duties of medical organizations to their employees, their clients, and their society?

Patients may also expect bioethicists to address another set of problems they have hardly embraced. Bioethics has recommended extensive changes in public policy, but it has scanted the ethical dilemmas individual human beings face when questions of health arise. Bioethics has routinely fobbed patients off with assurances that they are autonomous and will be guided by their own “values.” Patients who want help thinking through their ethical obligations may generally look elsewhere.

Some examples. (1) Bioethics has asked too infrequently about the morality of abortion in general or when abortion is morally permissible in a particular circumstance. (2) One of the largest ethical issues the baby-boom generation faces is what obligations adult children owe their enfeebled parents. Bioethics has barely edged into this subject.⁷³ (3) Bioethics has had strangely little to say about the value of human life and when it is legitimate to abandon

70. Norman A. Desbiens & Albert W. Wu, *Pain and Suffering in Seriously Ill Hospitalized Patients*, 48 J American Geriatric Society S183, S185 (2000).

71. There are differences among hospitals that suggest that noteworthy improvements in the treatment of pain are quite possible: “Patients at the worst performing hospital reported about 75% higher levels of pain than those at the hospital with the best performance. Anecdotally, at the best performing hospital, pain control had been a major emphasis for several years before the onset of SUPPORT.” *Ibid* at S186.

72. See, e.g., Daniel F. Chambliss, *Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics* (U Chicago Press, 1996).

73. There are some good starts. See, e.g., Hilde Lindemann Nelson & James Lindemann Nelson, *The Patient in the Family: An Ethics of Medicine and Families* (Routledge, 1995).

it. (4) Bioethicists have written a good deal about whether and how the definition of death should be manipulated in order to increase organ donations, but they have been much less concerned to identify and examine any duty to donate. (5) Finally, serious illness confronts most patients with a moral crisis in which they must think about whether their lives have been worth living and how their lives can be made worthwhile in the throes of disease.⁷⁴ With a few fine exceptions,⁷⁵ bioethicists have not helped patients grapple with these issues.

Patients will also be interested in the ethical distribution of medical resources. Bioethicists have of course paid some attention to rationing, but much work remains undone. The nature of that work is generally well known, but many issues have been virtually ignored. For instance, the primary device of bioethical policy—mandatory disclosure—benefits the well educated and well situated far more than the illiterate and poor. Disclosures are more useful to the former than the latter because the former are better able to understand them and understand how to use them. Furthermore, bioethical reforms divert resources from providing medical services. The well-off need not mind this because they already have access to good services. Those who are not prosperous are less fortunate; for them the diversion is usually a foolish allocation of resources.

This leads me to a final observation. Bioethics is about ethical obligations. But bioethics has a curiously narrow view of when people might owe each other duties. The obligations doctors and researchers contractually assume toward patients have been central to bioethics. But patients themselves think seriously about what they owe other people and about how they can live ethical lives. Bioethics has been so preoccupied with liberating patients from medical imperialism that it has hardly noticed the earnestness with which patients take their moral lives and obligations. No wonder we cannot adopt some system of health insurance, when we find it so difficult to think in terms of a duty to help other people.⁷⁶

I have argued that the crusade to put bioethical principles into law and policy seems to have failed in many serious ways. That failure has been little perceived and less discussed. In part, this is because bioethics has been unwilling to become an effective and ethical “policy science.” That is, it has been loathe to think about realistic ways of implementing its policies, about its policies’ costs, or about trade-offs among the goals of bioethics and other social

74. I discuss this in Carl E. Schneider, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions* (Oxford U Press, 1998).

75. E.g., Arthur W. Frank, *At the Will of the Body: Reflections on Illness* (Houghton Mifflin, 1991); Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (University of Chicago Press, 1995).

76. See Lois Shepherd, *Assuming Responsibility*, 41 Wake Forest L Rev 445 (2006).

goals in health affairs.

But the problem is also political and ideological. The political crusade against medical imperialism and the ideological embrace of the autonomy principle are powerful forces, forces that tend to suppress reflection about and criticism of bioethics. But the problem goes deeper. The apparent failure of bioethical policies raises disturbing questions we would rather not think about. First, if those policies don't work, must we return to the bad old days of medical paternalism? Second, it is hard to review the failure of those policies without sounding elitist, without seeming to sneer at the people who have not managed to make informed and acute medical decisions for themselves.

But this is what must make your study heroic. No one wants to return to the bad old days. And the failure of bioethical policies is not due to ignorant, stupid, and cowardly people. On the contrary. In my research among patients, I am always moved by the good sense, decency, and courage with which people suffering from dreadful illness live their lives. The problem lies not in the failings of some people; it lies in the limits of us all.

Bioethics has found comfort in its traditional enemy and its organizing principle. It is not pleasant to contemplate rethinking bioethics without the help of a familiar foe and an established principle. But it is time to try.