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# Bioethics with a Human Face<sup>†</sup>

CARL E. SCHNEIDER\*

Perhaps in ethics, the true route begins with practice, with deeds and doers, and moves only secondarily to reflection on practice. . . . Moreover, because this sort of philosophical reflection mirrors genuine conduct, ethics would not become wholly or purely abstract, would never reach to what we call ethical theory, because it would retain its connection with the concreteness and complexities of the moral life and the moral agent.

Leon R. Kass  
*Practicing Ethics*

What matters a great deal more is the fact that it was flimsily based, as I now think, on an *a priori* view of what human nature is like, both other people's and our own, which was disastrously mistaken.

John Maynard Keynes  
*My Early Beliefs*

This Article and the successor article I will shortly publish grow out of one reaction I have had to years of reading bioethical and legal literature.<sup>1</sup> Let me begin by putting the point in its simplest, even crudest, form: That literature too often discusses the problems of health care in so disembodied and denatured a way that the patients and physicians, the family and friends, the dread and the disease are quite abstracted from the scene. The result is a literature that critically limits itself and that crucially oversimplifies the issues it confronts.

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This Article began in a paper presented at a conference sponsored by the Poynter Center and the Indiana University School of Law—Bloomington. Other versions of that paper were presented at the Fifth Annual Bioethics Summer Retreat, at the Program for Society and Medicine, University of Michigan Medical School, and at a faculty workshop at the Arizona State University Law School. I am grateful to audiences at all these venues for their attentive and acute comments. I particularly benefitted from the illuminating responses to the paper I gave at the Indiana University symposium of Bernice H. Pescosolido and Peter Cherbas. I am also glad to be able to thank Renée R. Anspach, Alfred F. Conard, Joel Howell, Stanton D. Krauss, James Lindeman Nelson, Martin Pernick, Carl J. Schneider, Dorothy Schneider, Joan W. Schneider, and Carol Weisbrod for their perceptive and penetrating comments on earlier drafts of this manuscript. Finally, I am especially indebted to my colleagues and collaborators, Patricia D. White and Lee E. Teitelbaum, not just for their characteristically generous and thoughtful comments on this paper, but also for the ideas—too numerous and too integral to credit individually—which they have contributed to it. As they know, much in this paper grew out of the empirical project in which we are jointly engaged on how patients make medical decisions and out of our many conversations on these disturbing and absorbing topics.

1. In the highly interdisciplinary (or perhaps only motley) field of bioethics, it can be useful to confess one's disciplinary background. I write from the perspective of the academic lawyer.

There are, of course, reasons bioethical and even legal literature might tend to abstract people from its problems. Bioethics is, in part, a subset of ethics, and it is, in part, peopled by philosophers. It is a field and those are scholars whose special calling is to undertake abstract analyses of human dilemmas. And as Brody observes, the prominent analytic tradition in philosophy "has been powerful in condemning anecdotal or ad hoc reasoning as hopelessly subjective or intuitionistic and in insisting that reason in ethics requires that conclusions be logically deduced from more general principles."<sup>2</sup> Compounding this attention to the abstract is the philosopher's absorption with the normative, his desire, as James L. Nelson puts it, "not to ask what people want, as much as it is to ask what they should want."<sup>3</sup>

But even the abstract analysis of human problems cannot safely become too far detached from the reality of those problems, from the insistent complexity of human life. Further, bioethics, to say nothing of law, is also very much the study of applied ethics, and its practitioners include people—like doctors, lawyers, and ethicists employed by hospitals—who must be as concerned with empirics as ethics.<sup>4</sup>

Yet another force helps explain why the literature of bioethics and law has tended toward the abstract. Historically, bioethics has been vitally driven by a desire to tame the imperialism and arrogance of medicine. As is common in political battles, simple and forceful statements have worked better than complex and guarded ones. More specifically, a powerfully stated and too-often simple autonomy paradigm has become the central feature of bioethical thought and law. Yet, despite the undoubted and true importance of that paradigm, its reiteration has become stale, flat, and unprofitable, and its simplicities have become too costly.

Thus, in this Article, I try first to describe the "hyper-rationalism" of bioethics and of the law regulating the relationship between doctor and patient and then offer one way to treat that ailment. Hyper-rationalism is the tendency to believe, first, that people behave in ways that can so far be predicted *a priori* that empirical evidence about their behavior is superfluous and, second, that people think and act rationalistically, seeking always to maximize and exercise autonomy. Hyper-rationalism has contributed regrettably to a simplifying of bioethical and legal thought, to treating people as though they want essentially the same kinds of things and go about getting them in

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2. HOWARD BRODY, *STORIES OF SICKNESS* 144 (1987).

3. Private communication.

4. And so some of them have been, sometimes and to some extent. For instance, a standard introduction to bioethics—TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (3d ed. 1989)—cites some of the leading empirical studies and provides a generous sampling of case studies. The problem of informed consent has produced particular attention to the empirical aspects of a bioethical problem. *See, e.g.*, PAUL S. APPELBAUM ET AL., *INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE* (1987); Cathy J. Jones, *Autonomy and Informed Consent in Medical Decisionmaking: Toward a New Self-Fulfilling Prophecy*, 47 WASH. & LEE L. REV. 379 (1990); Alan Meisel & Loren H. Roth, *Toward an Informed Discussion of Informed Consent: A Review and Critique of the Empirical Studies*, 25 ARIZ. L. REV. 265 (1983).

essentially the same kinds of ways, to a view that human behavior is characterized by a predominantly logical approach to life's perplexities.

At this stage in the history of bioethics and law, we should be ready, and we surely need, to see the core problems of bioethics in all the factual and moral complexity of reality. I will argue that empirical research provides one useful way to bring more of that complexity back in. To illustrate concretely the usefulness of such research I will describe a literature which provocatively indicates that a substantial number of patients do not wish to make their own medical decisions. I will suggest that this literature raises questions that should cause us to think more deeply, rigorously, and richly about the problems of bioethics in general and about its autonomy paradigm in particular. Indeed, so fruitful are this literature and those questions that they cannot be cabined within a single article. Thus I will explore them at length in a subsequent piece.

### I. STATING THE PROBLEM

[The rationalist] does not neglect experience, but he often appears to do so because . . . of the rapidity with which he reduces the tangle and variety of experience to a set of principles which he will then attack or defend only upon rational grounds. He has no sense of the cumulation of experience, only of the readiness of experience when it has been converted into a formula . . . .

Michael Oakeshott  
*Rationalism in Politics*

It is no doubt true that you cannot get from *is* to *ought*. But you ought to know what *is* is before you say what *ought* ought to be. And many of us who write about bioethics can have only a faint sense of what that *is* is. Most of us are not doctors.<sup>5</sup> All of us are patients, but few of us are unfortunate enough to have wide personal dealings with doctors and hospitals. All of us—doctors, patients, lawyers, and ethicists—have readily to hand only our own limited and thus misleading experiences.

Bioethicists, like lawyers, constantly confront the danger of what I once called "hyper-rationalism."<sup>6</sup> Hyper-rationalism has both a methodological and a substantive aspect. In its former aspect, "[h]yper-rationalism is essentially the substitution of reason for information and analysis. It has two components: first, the belief that reason can reliably be used to infer facts where evidence is unavailable or incomplete, and second, the practice of interpreting facts through a [narrow] set of artificial analytic categories."<sup>7</sup> Hyper-rationalism,

5. And doctors seem curiously committed to an anecdotal approach to social and ethical issues. DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING* 7 (1991).

6. Carl E. Schneider, *Lawyers and Children: Wisdom and Legitimacy in Family Policy*, 84 MICH. L. REV. 919, 932-37 (1986).

7. *Id.* at 932. As Fox says of bioethics:

in other words, tempts us to believe that we can understand how people think and act merely by reasoning, and not by investigating. Hyper-rationalism seductively justifies discussing human behavior without doing the empirical work necessary to discover how people actually behave. Hyper-rationalism is the conceptualist's revenge for the world's complexity.

Methodological hyper-rationalism, I have said, offers a rationale for a way of understanding and writing about social problems. Substantive hyper-rationalism furnishes the assumptions about how people think and act that stand in for the information that might be garnered from empirical work. In bioethics, as in many other areas of human thought,<sup>8</sup> these assumptions see people as operating in highly rationalistic ways. They hold that people deliberate explicitly about their situations, that they do so in predominantly rational terms, that they are autonomy maximizers,<sup>9</sup> and that they have well-worked-out agendas which they need autonomy to maximize. The hyper-rationalists' assumptions further see people primarily as makers of decisions, reaching out for control over their lives.<sup>10</sup> Finally, while they do not always entirely abstract people from the social settings in which they live, they tend to simplify those settings radically.<sup>11</sup>

Combined, the assumptions of hyper-rationalism conduce to a view of human nature that airbrushes out life's complexity and that sees human nature and conduct as verging on the uniform. As Brody observes, "Some statements in the medical ethics literature suggest that there is basically one way to be sick, that sickness affects all sick individuals in this one way, and that

[O]rdered, cerebral armchair inquiry is given precedence, partly because the formalistic "data" it generates more closely fit the norms of bioethical logic and rationality than information gathered through first-hand research. Thought experiments are one of an array of cognitive techniques used in bioethics to distance and abstract itself from the human settings in which ethical questions are embedded and experienced, reduce their complexity and ambiguity, limit the number and kinds of morally relevant factors to be dealt with, dispel dilemmas, and siphon off the emotion, suffering, bewilderment, and tragedy that many medical moral predicaments entail for patients, families, and medical professionals.

Renée C. Fox & Judith P. Swazey, *Medical Morality Is Not Bioethics*, in *ESSAYS IN MEDICAL SOCIOLOGY* 645, 666 (1988). Or as one distinguished bioethicist observes, "[I]n the fields of medical ethics and bioethics, the theoretical views of Kant, Mill, and others are often invoked to give answers to clinical problems that the principles' abstract formulations cannot provide." JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 107 (1984).

8. Economics, of course, comes immediately but not exclusively to mind. For a sustained criticism of this aspect of social science thinking, see AMITAI ETZIONI, *THE MORAL DIMENSION: TOWARD A NEW ECONOMICS* (1988).

9. As the anthropologist Robert Murphy puts it, "The problems of dependence versus independence, of contingency versus autonomy, are not restricted to American culture—they are a universal aspect of all social relationships. The ability to survive on one's own and to maximize self-determination are essential ingredients of the basic drive to live." ROBERT F. MURPHY, *THE BODY SILENT* 202 (1990).

10. Etzioni associates this attitude with the "undersocialized view." That view "is closely linked to the enlightenment notion, which is very sanguine about an individual's ability to reason. It assumes that people set their own goals, in neatly patterned ways, and the ways they pursue their goals are open to evidence and to inferences drawn logically . . ." ETZIONI, *supra* note 8, at 13.

11. For criticisms of law's hyper-rationality, see Carl E. Schneider, *State-Interest Analysis and the Channeling Function in Privacy Law*, in *PUBLIC VALUES IN CONSTITUTIONAL LAW* 97 (Stephen E. Gottlieb ed., 1993); Carl E. Schneider, *State-Interest Analysis in Fourteenth Amendment "Privacy" Law: An Essay on the Constitutionalization of Social Issues*, 51 *LAW & CONTEMP. PROBS.* 79 (1988).

therefore one can usefully generalize, for ethical purposes, among all such cases without inquiring too finely into the details."<sup>12</sup> Similarly, the law of bioethics operates in capacious but indiscriminating categories. The duty of informed consent, for example, applies by its terms to all but a few medical decisions (those involving medical emergencies or patients who would be injured by a disclosure). As Schuck writes, "[w]ith some relatively narrow exceptions the law treats all patients and physicians the same; it posits an abstracted, objectively defined 'prudent patient' as the consumer of information and the maker of choices, and conforms all physicians' legal obligations to this uniform abstraction."<sup>13</sup>

Hyper-rationalism's assumptions also conduce to the view that patients make decisions in highly rationalistic ways. Even some work in medical sociology and social psychology is not immune from this defect. Thus Janis writes:

The theoretical concepts that have been dominant in the literature on decision making for over 25 years are based on cognitive theories, such as 'game theory' and 'subjective expected utility' (SEU) theory, which assume that people make deliberate choices on a rational basis, taking account of the values and the probabilities of the consequences to be expected from choosing each of the available alternatives.<sup>14</sup>

As empiricists in fields ranging from sociology to psychology to anthropology have been at pains to show, this view exaggerates human rationality and understates the role of social and cultural factors in patients' lives.<sup>15</sup>

If students of human behavior have too often succumbed to this consequence of hyper-rationalism, we should not be surprised to find lawyers and bioethicists following suit.<sup>16</sup> Consider, for instance, how they seem to believe people should and can make decisions. The AMA, for instance, has thought that the "decision whether to permit or to perform a transplantation procedure . . . must be a reasoned, intellectual decision, not an emotional decision."<sup>17</sup> Or, as one influential bioethicist writes, "Consent must be voluntary and

12. BRODY, *supra* note 2, at 144. He continues, "The extreme form of such a statement is something like 'All illness represents a state of diminished autonomy'. . . ." *Id.* (quoting M. S. Komrad, *A Defence of Medical Paternalism: Maximising Patients' Autonomy*, 9 J. MED. ETHICS 38 (1983)).

13. Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 957 (1994).

14. Irving L. Janis, *The Patient as Decision Maker*, in HANDBOOK OF BEHAVIORAL MEDICINE 326, 327 (W. Doyle Gentry ed., 1984).

15. For an instructive survey of those criticisms, see Ronald C. Kessler et al., *Social Psychology and Health*, in SOCIOLOGICAL PERSPECTIVES ON SOCIAL PSYCHOLOGY (Karen Cook et al. eds., 1994). For explorations of the limits on human rationality in making decisions, see DANIEL KAHNEMAN ET AL., JUDGMENT UNDER UNCERTAINTY: HEURISTICS AND BIASES (1982). For an exploration of the emotional context of human decisions, with special attention to the problems of medical patients, see IRVING L. JANIS & LEON MANN, DECISION MAKING: A PSYCHOLOGICAL ANALYSIS OF CONFLICT, CHOICE, AND COMMITMENT 16 (1977). For a first-rate treatment of the social context of one kind of medical decision, see Bernice A. Pescosolido, *Beyond Rational Choice: The Social Dynamics of How People Seek Help*, 97 AM. J. SOC. 1096, 1106-07 (1992).

16. For a particularly good examination of the tendency of modern bioethics to abstract problems from their human and social reality and to think in hyper-rationalistic terms about them, see Leon R. Kass, *Practicing Ethics: Where's the Action?*, HASTINGS CENTER REP., Jan.-Feb. 1990, at 5.

17. American Medical Association Judicial Council, *Ethical Guidelines for Organ Transplantation* 205 JAMA 341 (1968).

free—the product of deliberative reflection on all possible courses of action.”<sup>18</sup> Or again, as two other influential bioethicists suggest, “Autonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize the values.”<sup>19</sup>

Hyper-rationalism’s substantive assumptions could be true, but that has hardly been demonstrated. And they are much likelier to be false. Their picture of human nature is far too simple, far too disembodied to be convincing. They present a bloodless, flat, distant, abstract, depersonalized, impoverished view of the way people think, feel, and act, of the social circumstances in which people live, of the ethical lives they lead. And hyper-rationalism’s simplifications are particularly injurious in bioethics, a field that treats people in their least rational moments, in their most emotional travails, in their most contextual complexity.

Hyper-rationalism, of course, has its uses. It promotes the kind of generalization that frees courts and commentators to reason logically about the normative problems that are, after all, one of their central concerns. And some simplification of life’s complexity is surely necessary if human problems are to be handled practically and promptly, if comprehensible rules are to be devised, if useful precedent is to be developed. But bioethicists and lawyers should want to insinuate as much of that complexity as possible into their normative discourse. A failure to do so perilously distances norms from the people and circumstances they seek to govern and serve.

This is a peril with which law is all too familiar. Indeed, one of the most illuminating bodies of modern legal writing is the scholarship which makes sport of the idea (that seems so natural and right to lawyers and law professors) that the law makes rules and that people know about them, accept them, and respond to them in a considered and rational way. The seminal and classic work in this sobering genre is Stewart Macaulay’s *Non-Contractual Relations in Business: A Preliminary Study*.<sup>20</sup>

Macaulay interviewed suppliers and purchasers in Wisconsin to see how they used contracts and how the law of contracts influenced them. He found that firms did not conceive of themselves as using contract law (even when, in legal terms, they were) and that disputes were “frequently settled without reference to the contract or potential or actual legal sanctions.”<sup>21</sup> Quite the contrary, businessmen relied on their own system of norms and on informal sanctions. As one of them crushingly said, ““You don’t read legalistic contract clauses at each other if you ever want to do business again. One doesn’t run

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18. Arthur L. Caplan, *Informed Consent and Provider/Patient Relationships in Rehabilitation Medicine*, in IF I WERE A RICH MAN COULD I BUY A PANCREAS? 240, 245 (1992).

19. Ezekiel J. Emanuel & Linda L. Emanuel, *Four Models of the Physician-Patient Relationship*, 267 JAMA 2221, 2225 (1992).

20. Stewart Macaulay, *Non-Contractual Relations in Business: A Preliminary Study*, 28 AM. SOC. REV. 36, 55 (1963).

21. *Id.* at 61.

So far, I have made a general case that in our thinking about legal and bioethical issues, we are prone to a hyper-rationalism that distorts our understanding of reality and that thus warps our normative thinking. I have further argued that empirical research can help mend these defects. But the best way of demonstrating the usefulness of the approach I advocate is by example. Therefore, I will now briefly explore some of the hyper-rationalistic assumptions on which the law of bioethics has relied. Then, I will draw attention to a body of empirical data that raises provocative and stimulating questions about those assumptions.

I begin with the centerpiece of bioethics—its autonomy paradigm. "Paradigms," Kuhn suggests, "gain their status because they are more successful than their competitors in solving a few problems that the group of practitioners has come to recognize as acute."<sup>46</sup> Bioethics was born out of a crisis of imperialism in biomedical research and medical treatment.<sup>47</sup> It is thus unsurprising that, as Fox writes, "from the outset, the conceptual framework of bioethics has accorded paramount status to the value-complex of individualism, underscoring the principles of individual rights, autonomy, self-determination, and their legal expression in the jurisprudential notion of privacy."<sup>48</sup> Even where the issue is the just allocation of scarce resources, "[t]he view of distributive justice underlying it is structured around an individual, rights-oriented conception of the general or common good, in which greater importance is assigned to equity than to equality."<sup>49</sup>

Of course, describing any field's paradigm is challenging, and bioethics' paradigm is particularly elusive because that subject is compounded from several diverse fields. Further, it is divided between "advocates" and "academics" (although it is a passionate field, and sometimes one can scarcely tell the two groups apart).<sup>50</sup> As one might anticipate, the academics tend to articulate the autonomy paradigm with greater sophistication, care, and subtlety than the advocates.<sup>51</sup> But "no important thought achieves social power undegraded."<sup>52</sup> The intricate and somber refinement of a Freud is soon

46. THOMAS S. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* 23 (1970). It is difficult for a late twentieth-century academic to think about the development of a field of scholarship without advertising to Kuhn's magisterial work. Perhaps that work applies better to scientific scholarship than to scholarship in other fields. Perhaps it applies with some awkwardness to a field simultaneously as deeply theoretical and as frankly practical as bioethics. Perhaps it does not even satisfactorily describe all scientific work. But it has enormous resonance, and it will prove a useful point of embarkation. For a recent survey of Kuhn's work, see PAUL HOYNINGEN-HUENE, *RECONSTRUCTING SCIENTIFIC REVOLUTIONS: THOMAS S. KUHN'S PHILOSOPHY OF SCIENCE* (1993).

47. For the story of the origins of bioethics, see DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING* (1991).

48. Fox, *supra* note 42, at 206.

49. *Id.*

50. On this division, see Daniel Wikler, *What Has Bioethics to Offer Health Policy?*, 69 *MILBANK Q.* 233 (1991).

51. For example, Beauchamp and Childress labor to make it clear that there is more to bioethics than the autonomy paradigm. BEAUCHAMP & CHILDRESS, *supra* note 4.

52. Carl E. Schneider, *Moral Discourse and the Transformation of American Family Law*, 83 *MICH. L. REV.* 1803, 1846 (1985).



transmuted into the remissive banalities of psychobabble.<sup>53</sup> The cautious complexities of constitutional rights doctrine are readily debased into arguments that professional baseball players have a constitutional right to chew tobacco while playing ball. Thus the advocate's blunter versions are in some ways the more consequential formulations of the paradigm, since it is they that dominate the world in which medical policies are formulated and social decisions are made and which are likeliest to beguile the public mind.

In any event, there is no doubt about the triumph of the autonomy paradigm. As Caplan observes, "there are relatively few bioethicists who argue that respect for autonomy is not the preeminent value governing the actions of health-care providers."<sup>54</sup> He continues colorfully,

The Freddy Kruger of bioethics for the better part of two decades has been the doctor who pushes his or her values onto the patient . . . . This devil has been completely exorcised and a large part of contemporary bioethics scholarship seems to be devoted to the task of assuring that the paternalistic doctor stays dead and buried . . . .<sup>55</sup>

It is perfectly true that in that most canonical expression of bioethic's paradigms—what is jocularly called the Georgetown mantra—other considerations are recited. However, it is abundantly plain which principle predominates: And now abideth beneficence, social justice, and autonomy, these three; but the greatest of these is autonomy. Thus, Fox observes that even the "benefiting of others advocated in bioethical thought is circumscribed by respectful deference to individual rights, interests, and autonomy; and minimizing the harm done to individuals is more greatly accentuated than the maximization of either personal or collective good."<sup>56</sup>

In my own field—the law governing medicine—it has been said that "Anglo-American law starts with the premise of thorough-going self-determination."<sup>57</sup> Certainly autonomy has enjoyed an increasingly expansive role in that law during the life span of bioethics. The doctrine of informed consent, it is worth remembering, is essentially an innovation of the last three decades.<sup>58</sup> In recent years, numerous state legislatures have labored to enhance patients' autonomy by authorizing various kinds of advance directives. Similarly, Congress a few years ago enacted the Patient Self Determination Act, which basically requires hospitals and nursing homes to

53. See, e.g., PHILIP RIEFF, *FREUD: THE MIND OF THE MORALIST* (1979); PHILIP RIEFF, *THE TRIUMPH OF THE THERAPEUTIC: USES OF FAITH AFTER FREUD* (1966).

54. See, e.g., *Can Autonomy Be Saved?*, *supra* note 26, at 257.

55. *Id.* at 259.

56. Fox, *supra* note 42, at 206-07.

57. *Natanson v. Kline*, 350 P.2d 1093, 1104 (Kan. 1960).

58. For a somewhat tendentious history of that doctrine, see KATZ, *supra* note 7, at 41-84. For a well informed and more complex view of that history, see Martin S. Pernick, *The Patient's Role in Medical Decisionmaking: A Social History of Informed Consent in Medical Therapy*, in *MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP* (3 President's Comm. for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982) [hereinafter *President's Comm.*].

to lawyers if he wants to stay in business because one must behave decently."<sup>22</sup>

Another illuminating study reaching much the same kind of conclusion about the relevance of law's assumptions and forms to people's lives is Robert C. Ellickson's striking study of ranchers and farmers in Shasta County, California.<sup>23</sup> Ellickson set out to test the Coase Theorem's principle that people will reach an economically efficient solution to their disputes whatever the law's allocation of tort liability. Ellickson found that the allocation of liability actually does not matter when wandering cattle damage a farmer's crops, but not because people bargain to achieve economic efficiency. Rather, disputes are generally avoided in the service of an informally accepted norm of neighborliness and reciprocity, a norm enforced by the community's own homemade informal sanctions.<sup>24</sup>

In short, a chastening literature "reveals that, to the lawyer's chagrin, businesses resist using contracts, ranchers do not know what rules of liability govern damage done by wandering cattle, suburbanites do not summon the law to resolve neighborhood disputes, engaged couples do not know the law governing how they will own property when they marry, citizens repeatedly reject the due process protections proffered them, and, what is worse, all these people simply don't care what the law says."<sup>25</sup> This literature vividly demonstrates the perils of the hyper-rationalist approach even in areas like commercial life, which might be thought safe places to apply it.

The law regulating medicine abounds in its own examples of this provoking phenomenon. For example, the law's principal bioethical reforms have been used far less than their advocates anticipated and hoped. Caplan reports, for instance, "No more than 10 percent of the population has either a living will or a durable power of attorney."<sup>26</sup> He adds, "Similarly dismal statistics are reported for the practices surrounding the issuance of DNR (do-not-resuscitate), DNI (do-not-intubate), and DNT (do-not-treat) orders in hospitals and nursing homes."<sup>27</sup> Thus one study found that "the enactment of DNR legislation in the State of New York appears to have had little effect on the frequency of CPR and on the degree of patient or family involvement in the

22. *Id.*

23. ROBERT C. ELICKSON, *ORDER WITHOUT LAW: HOW NEIGHBORS SETTLE DISPUTES* (1991).

24. *Id.* For further accounts and analyses of this literature, see ROBERT H. MNOOKIN ET AL., *IN THE INTEREST OF CHILDREN: ADVOCACY, LAW REFORM, AND PUBLIC POLICY* (1985); Lynn A. Baker & Robert E. Emery, *When Every Relationship Is Above Average: Perceptions and Expectations of Divorce at the Time of Marriage*, 17 L. & HUM. BEHAV. 439 (1993); Carl E. Schneider, *Lawyers and Children: Wisdom and Legitimacy in Family Policy*, 84 MICH. L. REV. 919 (1986); Carl E. Schneider, *Rethinking Alimony: Marital Decisions and Moral Discourse*, 1991 B.Y.U. L. REV. 197, 203-09; Carl E. Schneider, *Social Structure and Social Control: On the Moral Order of a Suburb*, 24 L. & SOC. REV. 875 (1990).

25. Carl E. Schneider, *Bioethics in the Language of the Law*, HASTINGS CENTER REP. (forthcoming 1994).

26. Arthur L. Caplan, *Can Autonomy Be Saved?*, in IF I WERE A RICH MAN COULD I BUY A PANCREAS? 256, 261 (1992) (citation omitted) [hereinafter *Can Autonomy Be Saved?*].

27. *Id.*

DNR decision at our institution."<sup>28</sup> Caplan also argues that the experiment of organ-donor cards "has been a failure," since despite the nearly universal provision of a donor form on the back of one's driver's license, "no more than 20 percent of all Americans have signed it."<sup>29</sup> And Caplan reviews a number of studies that "indicate that despite the enactment of legislation in forty-four states requiring requests to be made of family members about organ and tissue donation when someone dies in a hospital setting, more than a third of all hospitals never do so, and an even larger number do so only sporadically."<sup>30</sup>

Similarly, there is evidence that, despite the love and labor that have been poured into it, the law of informed consent rarely results in significant verdicts for plaintiffs, since "few patients sue physicians in general, even fewer sue claiming lack of informed consent, and yet fewer prevail on that theory."<sup>31</sup> One prominent scholar concludes glumly that that law "has had little impact on patients' decision-making either in legal theory or medical practice."<sup>32</sup> Some substantiation of this lies in the fact that "the empirical and anecdotal studies of patients who refuse treatment almost never portray the process of obtaining informed consent as playing a causative role."<sup>33</sup>

A disjunction between the law's assumptions and the realities of practice may be seen in yet other areas of medical law. Frequent and menacing though tort suits may seem to doctors, "for every 8 potentially valid claims, only 1 claim [is] actually filed."<sup>34</sup> Indeed, "[e]ven when we narrowed our focus to the more serious and 'valuable' tort claims—iatrogenic injuries to patients under seventy that produced disabilities (including death) lasting six months or more—we still found that for every 3 such events there was only 1 tort payment."<sup>35</sup> Finally, there is (perhaps reassuring) evidence that "the existence of Good Samaritan legislation made no difference to the willingness of physicians to stop and assist."<sup>36</sup>

This literature, then, should alert us to the dangers of hyper-rationalism, to the perils of believing unaided ratiocination can allow us to understand how people conceive of their problems, organize their lives, resolve their disputes, and respond to legal norms. But what is the antidote to hyper-rationalism? There are several. For instance, Brody writes that philosophy of medicine "can indeed advance by . . . abstract discussions; but it can advance only so

28. Russell S. Kamer et al., *Effect of New York State's Do-Not-Resuscitate Legislation on In-Hospital Cardiopulmonary Resuscitation Practice*, 88 AM. J. MED. 108, 109-10 (1990).

29. *Can Autonomy Be Saved?*, *supra* note 26, at 262-63.

30. *Id.* at 265.

31. APPELBAUM ET AL., *supra* note 4, at 46.

32. Jay Katz, *Informed Consent—A Fairy Tale? Law's Vision*, 39 U. PITT. L. REV. 137, 139 (1977).

33. APPELBAUM ET AL., *supra* note 4, at 202.

34. PAUL C. WEILER, *MEDICAL MALPRACTICE ON TRIAL* 13 (1991).

35. *Id.*

36. BARRY R. FURROW ET AL., *HEALTH LAW: CASES, MATERIALS AND PROBLEMS* 187 (2d ed. 1991). I do not mean to suggest that it is only lawyers who see the world through distorting lenses. For an examination of the misperceptions doctors often have of the law, see Marshall B. Kapp & Bernard Lo, *Legal Perceptions and Medical Decision Making*, 64 MILBANK Q. 163 (1986).

far. At some point we will require a richer context for the discussion to proceed fruitfully. This context can be provided by stories of sickness."<sup>37</sup>

This attractive and profitable solution, of course, has its formal, well-established, and central counterparts. Casuistry is an ancient and still honorable mode of ethical discourse.<sup>38</sup> And cases lie at the very heart of our common-law and constitutional method. But necessary though those methods surely are, they are not by themselves sufficient. Too much depends on the way the case is selected for study, on the richness of the problems the case presents, on the amount of information that can be obtained about it. And ultimately, a single case, or even a few cases, must be unrepresentative of the sweep of cases the world invariably spawns.

We need, then, to inhabit all the mansions available in the house of bioethics. And among the most deserted of those mansions is that of empirical research. Judicial opinions dealing with bioethical issues rarely deal thoroughly with empirical evidence, or even with what effect judicial doctrines have. As Schuck notes, for example, "the cases evince little systematic judicial interest in the [informed consent] doctrine's actual consequences, especially its costs. Instead, courts tend to invoke the values of autonomy and improved decisionmaking and then analyze the implications of those values . . ."<sup>39</sup> Similarly, "[i]n *Tarasoff [v. Regents of the University of California]*<sup>40</sup>, as in other well known tort decisions, a court announced a rule designed to change private behavior without reliable data regarding the practices it was intending to change, the extent of the problem it was trying to remedy, or the costs which the proposed cure would impose."<sup>41</sup> Commentators are perhaps less prone to this failing, but it is still easy to find lengthy articles, to say nothing of books, on bioethical issues which are unbesmirched by data.

Yet such research offers a breadth, rigor, and precision of understanding that is available in no other way. It provides a disciplined way of reviewing our assumptions and a systematic means of identifying neglected issues. In sum, empirical research provides a fruitful means of winning a more detailed, complex, and accurate picture of what patients want, think, and do which can deepen—and darken—our understanding of bioethical problems.<sup>42</sup>

All this being said, let me be the first to acknowledge the inevitable and substantial difficulty of drawing solid conclusions about the psychological and

37. BRODY, *supra* note 2, at x. For further ruminations of the centrality of stories in medicine, see, e.g., KATHRYN HUNTER, *DOCTORS' STORIES: THE NARRATIVE STRUCTURE OF MEDICAL KNOWLEDGE* (1991).

38. For a helpful recent discussion of that tradition in the bioethical context, see John D. Arras, *Getting Down to Cases: The Revival of Casuistry in Bioethics*, 16 J. MED. PHIL. 29 (1991).

39. Schuck, *supra* note 13, at 939.

40. 551 P.2d 334 (Cal. 1976).

41. Daniel J. Givelber et al., *Tarasoff, Myth and Reality: An Empirical Study of Private Law in Action*, 1984 WIS. L. REV. 443, 444 (footnote omitted).

42. For an extended description of the distance between bioethics and the social sciences, see Renée C. Fox, *The Evolution of American Bioethics: A Sociological Perspective*, in SOCIAL SCIENCE PERSPECTIVES ON MEDICAL ETHICS 201 (George Weisz ed., 1990).

social reality of bioethical problems from the empirical evidence that is currently available.<sup>43</sup> Empirical work relating to bioethics has all too frequently been poorly planned and performed. It has often been designed to test quite narrow questions, and those questions have not always been the ones most urgent to bioethicists. That work has not developed according to any larger plan, but has been done in response to a smorgasbord of discrete problems in a hodgepodge of fields extending from law to sociology and psychology to clinical medicine. Further, given the variety of medical decisions that are made, the variety of contexts in which they occur, and the variety of people who make them, it is all too likely that a study of one situation will be a poor guide to others. Empirical work of this kind is also time-bound, a particularly acute problem in an era and in areas as marked by fulminant change as today's medicine, bioethics, law, and society. Finally, because life is complicated and research is confoundingly difficult, even relevant and ably done studies can produce results that bafflingly conflict with the conclusions of other competently done research.<sup>44</sup>

But I do not want to concede too much. Good empirical research into bioethical issues is being done.<sup>45</sup> And it is better to have some information than none: Ultimately, we are wiser to use the best empirical evidence we can muster than idly to rely on unexamined assumptions about an uncertain reality. In any event, in this Article I am proposing that we should use these empirical data not so much as infallible guides to what happens, but to introduce more of the world's complexity into our thinking, both for present consideration and future research.

## II. HYPER-RATIONALISM AND AUTONOMISM IN BIOETHICS AND LAW

Truth is never pure and seldom simple.

Oscar Wilde

*The Importance of Being Earnest*

43. Indeed, it is always difficult to find adequately reliable empirical evidence and to draw useful conclusions from it, as a massive literature attests. For a brief but knowledgeable introduction to that literature, see CHARLES E. LINDBLOM & DAVID K. COHEN, *USABLE KNOWLEDGE: SOCIAL SCIENCE AND SOCIAL PROBLEM SOLVING* (1979).

44. For an example of such a result, see Debra L. Roter & Judith A. Hall, *Studies of Doctor-Patient Interaction*, 10 ANN. REV. PUB. HEALTH 163 (1989). See Meisel & Roth, *supra* note 4, at 265, for a relentless demonstration of the problems with empirical research in many kinds of bioethical problems.

45. Recent monographic examples include, but are not limited to, RENÉE ANSPACH, *DECIDING WHO LIVES: FATEFUL CHOICES IN THE INTENSIVE CARE NURSERY* 36 (1993); CHARLES L. BOSK, *ALL GOD'S MISTAKES: GENETIC COUNSELING IN A PEDIATRIC HOSPITAL* (1992); ROBERT ZUSSMAN, *INTENSIVE CARE: MEDICAL ETHICS AND THE MEDICAL PROFESSION* (1992). Janis concludes that "a substantial number of studies can now be drawn upon to provide promising leads for explaining health-related behavior and for developing practical applications . . ." Janis, *supra* note 14, at 343. Anspach and Zussman provide illuminating apologies for the usefulness of social science in bioethics; Bosk presents somewhat more guarded reflections on the same topic. Robert A. Pearlman et al., *Contributions of Empirical Research to Medical Ethics*, 14 THEORETICAL MED. 197 (1993), shows how specific empirical studies have promoted discussion of some specific ethical issues. More broadly, see also Fox, *supra* note 42, at 206.

give their clients an opportunity to make advance directives.<sup>59</sup> In a long series of cases posing the question when medical treatment may be withdrawn, state courts have generally striven to effectuate the supposed desires of the patient. Even *Cruzan v. Director, Missouri Department of Health*,<sup>60</sup> which has been assailed as curtailing rights of autonomy, can be understood as quite compatible with them. In that case, for instance, the Supreme Court unanimously endorsed the proposition that patients have some kind of constitutional status in making medical decisions.<sup>61</sup> And the majority's holding was essentially based not on the absence of Cruzan's autonomy rights, but on the presence of reasonable doubts about how she might have wished to exercise them.<sup>62</sup>

In the particular area of bioethics to which this Article is directed—that is, medical decision-making—patient autonomy is strongly the dominant paradigm.<sup>63</sup> In “contemporary medical ethics, . . . engaging the patient as an active participant in medical decision making is seen as particularly important,”<sup>64</sup> and “[i]n recent decades there has been a call for greater patient autonomy or, as some have called it, ‘patient sovereignty,’ conceived as patient *choice* and *control* over medical decisions.”<sup>65</sup> Unfortunately, most bioethicists have been thoroughly (if understandably) vague about the precise nature and scope of that autonomy, about how it should be used, and about

59. 42 U.S.C. §§ 1395(cc)(f), 1396(a)(w). In addition, of course, many public and private health-care providers have written rules (governing DNR orders, for example) and established programs (ethics committees, for instance), intended at least partly to protect patients' autonomy.

60. *Cruzan*, 497 U.S. 261 (1990). For some sound views of the constitutional issues in the case, see Yale Kamisar, *Right to Die? When Is There No Constitutional 'Right to Live'?*, 25 GA. L. REV. 1203 (1991); John Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139 (1991). I analyze the case in Carl E. Schneider, *Cruzan and the Constitutionalization of American Life*, 17 J. MED. & PHIL. 589 (1992).

61. As the Court put it, “a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment . . . .” *Cruzan*, 497 U.S. at 278.

62. I do not mean to suggest that the law has failed to recognize some of the important reasons patient autonomy must be limited. For a helpful and refreshing argument that “autonomy does not seem to be as dominant a value as rhetoric would suggest,” see Roger B. Dworkin, *Medical Law and Ethics in the Post-Autonomy Age*, 68 IND. L.J. 727, 728 (1993).

63. I am referring here, of course, to what bioethicists and lawyers say, not to what doctors do. What doctors have historically done differs markedly from what bioethicists would now have them do. But there is some evidence of notable changes in what doctors do. Zussman, for instance, reports that “the notion of rights in medicine . . . has . . . become part of the culture of medicine itself.” ZUSSMAN, *supra* note 45, at 85. He concludes that the “notion of rights as a broad cultural concept (the acceptance of which is among the indirect effects of the legal doctrine) has had far-reaching consequences, including, most important, an empowerment of the patient . . . .” *Id.* at 81. Caplan notes that “[d]octors and nurses report in survey after survey that they support the concept of advance directives . . . .” *Can Autonomy Be Saved?*, *supra* note 26, at 261. For a less sanguine evaluation of changes in attitudes toward patient autonomy in decisions to terminate treatment, see David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101 (1992). He believes that a “reasonable argument can be made that professional resistance to patient autonomy has so far prevailed and that changes in the treatment of the dying reflect changes in physician attitudes more than changes in the way end-of-life decisions are made.” *Id.* at 2103.

64. Lachlan Forrow et al., *Science, Ethics, and the Making of Clinical Decisions*, 259 JAMA 3161, 3166 (1988).

65. Emanuel & Emanuel, *supra* note 19, at 2223 (emphases in original) (citation omitted).

how doctors and patients are to put the principle into practice.<sup>66</sup> However, the standard view broadly makes the physician the proposer and the patient the disposer. Brock provides a particularly lucid, measured, and moderate statement of that view:

Most simply put, the physician's role is to use his or her training, knowledge, and experience to provide the patient with facts about the diagnosis and about the prognoses without treatment and with alternative treatments. The patient's role in this division of labor is to provide the values—his or her own conception of the good—with which to evaluate these alternatives, and to select the one that is best for himself or herself.<sup>67</sup>

Further, bioethicists generally unite in wanting the patient's choice to be autonomous in quite a strong sense of that term. Thus, for example, Beauchamp and Childress look for a decision in which "a patient or subject with substantial *understanding* and in substantial *absence of control* by others *intentionally authorizes* a professional to do something."<sup>68</sup>

This standard view of the centrality of patient autonomy and its predominance in medical decisions is enacted into law in the doctrine of informed consent.<sup>69</sup> That doctrine assumes that "it is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests seem to lie."<sup>70</sup> Medical decisions may only be made with the patient's consent. Once again, consent is intended in a strong sense: "True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each."<sup>71</sup> It is the goal of the doctrine of informed consent to secure "the patient's right of self-determination on [a] particular therapy"<sup>72</sup> and to "enable the patient to chart his course understandably" by

66. Instead of precision, readers of bioethical writing must often settle for such uninformative terms as "shared," or "collaborative," or "participatory." The Emanuels have made a step in the right direction by trying to construct ideal types of medical decisions. *Id.* at 2221. They identify a "paternalistic" model in which the doctor decides what is best, subject to the patient's assent; an "informative" model in which the doctor presents information to the patient and the patient makes the decision; an "interpretive" model in which the doctor's job is to help patients discover what they want and how best to get it; and a "deliberative" model in which doctors work with patients to "help the patient determine and choose the best health-related values that can be realized in the clinical situation." *Id.* at 2221-22. While the Emanuels do little to identify proponents of these models, they do conclude that there has been a "shift toward the informative model." *Id.* at 2223.

67. Dan W. Brock, *The Ideal of Shared Decision Making Between Physicians and Patients*, 1 KENNEDY INST. ETHICS J. 28, 28 (1991). Brock's own views on the subject are engaging and well worth reading. For similar descriptions of how medical decisions ought to be made, see, e.g., Richard Sherlock, *Reasonable Men and Sick Human Beings*, 80 AM. J. MED. 2, 2 (1986). One of the standard internal medicine textbooks speaks of "a more equal relationship of shared decision making in which physicians provide information and counseling that allows competent adult patients to make their own choices." Mark Siegler & Peter A. Singer, *Clinical Ethics*, in 1 TEXTBOOK OF INTERNAL MEDICINE 3, 4 (William N. Kelley ed., 2d ed. 1992).

68. BEAUCHAMP & CHILDRESS, *supra* note 4, at 76 (emphases in original).

69. For an imposing list of articles to this effect, see Marjorie M. Shultz, *From Informed Consent to Patient Choice: A New Protected Interest*, 95 YALE L.J. 219, 226 n.30 (1985).

70. *Canterbury v. Spence*, 464 F.2d 772, 781 (D.C. Cir. 1972) (citation omitted).

71. *Id.* at 780 (citation omitted).

72. *Id.* at 784 (citation omitted).

assuring him some "familiarity with the therapeutic alternatives and their hazards."<sup>73</sup>

The reaction of commentators to the law of informed consent confirms the elevated status of the autonomy paradigm and the high hopes autonomists have for patient participation in medical decisions. The conventional wisdom is that that law is wretchedly inadequate to its vocation of promoting patients' autonomy. Katz, for instance, calls that law "largely a charade"<sup>74</sup> that is "substantially mythic and fairy tale-like as far as advancing patients' rights to self-decisionmaking is concerned" and that "only has made a bow toward a commitment to patients' self-determination."<sup>75</sup> Appelbaum, Lidz, and Meisel call informed consent "a doctrine and a set of practices that compromise all values and satisfy none in their entirety."<sup>76</sup> Shultz is one of many who wish to broaden its scope largely. (She would require doctors to tell patients not just about proposed treatments, but also about possible medical inquiries the physician decides not to pursue.)<sup>77</sup> More generally, commentators widely believe that "[t]he rise of patients' rights, both in law and ethics, instigated a revolution not yet completed,"<sup>78</sup> a "revolution in medical relationships [which] remains incomplete and embattled,"<sup>79</sup> a revolution in which "[t]he struggle is to recognize patients' rights."<sup>80</sup>

In sum, the overwhelming weight of bioethical opinion thus endorses not just the autonomy principle, but quite a potent version of it. The autonomy paradigm continues to flourish, planted as it is in the fertile soil of American rights thinking, anchored as it is by roots that run deep into the structure of American law, and tended as it is by legions of votaries.<sup>81</sup> That paradigm

73. *Id.* at 781 (citation omitted).

74. KATZ, *supra* note 7, at 99.

75. Katz, *supra* note 32, at 174. Echoing Katz, Brennan writes that "doctors have consistently sought to maximize their own paternalistic prerogatives. The notion of informed consent thus remains a fairy tale." Troyen A. Brennan, *Silent Decisions: Limits of Consent and the Terminally Ill Patient*, 16 L. MED. & HEALTH CARE 204, 204 (1988) (citation omitted).

76. APPELBAUM ET AL., *supra* note 4, at 130.

77. Shultz, *supra* note 69. For other criticisms of the doctrine of informed consent by legal commentators, see, e.g., HOWARD BRODY, THE HEALER'S POWER 83-119 (1992); Howard Brody, *Transparency: Informed Consent in Primary Care*, HASTINGS CENTER REP., Sept.-Oct. 1989, at 5; Jones, *supra* note 4; Alan Meisel, *A "Dignitary Tort" as a Bridge Between the Idea of Informed Consent and the Law of Informed Consent*, 16 L. MED. & HEALTH CARE 210 (1988).

78. Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 MD. L. REV. 798, 824 (1991).

79. *Id.* at 857.

80. *Id.* at 855.

81. For a critical examination of the centrality of rights thinking in American politics, law, and life, see MARY ANN GLENDON, RIGHTS TALK: THE IMPOVERISHMENT OF POLITICAL DISCOURSE (1991). For an argument stressing that centrality, but arguing that inchoate alternatives yearn to break through, see ROBERT N. BELLAH ET AL., HABITS OF THE HEART: INDIVIDUALISM AND COMMITMENT IN AMERICAN LIFE (1985). For a study of rights thinking at the intersection of bioethics and law, see Schneider, *supra* note 60; and Carl E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 CAL. L. REV. 151 (1988) [hereinafter *Rights Discourse*]. For an examination of the role of rights in medical decisions, see ZUSSMAN, *supra* note 45, at 81-97. Zussman believes that the "notion of rights" has "since about 1970, become part of the culture of medicine itself." *Id.* at 85.

This emphasis on the distinctively American quality of the autonomy paradigm is not accidental. There are few if any other countries in the world in which autonomy has assumed so powerful a position



rests on the methodologically and substantively hyper-rationalistic assumption that autonomy is what people primarily and pervasively want and need. Correspondingly, the law of bioethics seems to assume that its principal task is to remove impediments to the exercise of autonomy, that once those impediments are removed, people will naturally gather evidence about the risks and benefits of each medical choice, will apply that evidence to their values, and will reach a considered and autonomous decision.

Nevertheless, we may now have reached a relatively late period in what Kuhn might call the "normal science" of the autonomy paradigm. A large part of bioethical thought in recent years has involved working out what "autonomy" might mean. That work has produced the expected unexpected: "Normal science does not aim at novelties of fact or theory and, when successful, finds none. New and unsuspected phenomena are, however, repeatedly uncovered by scientific research . . ." <sup>82</sup> This has now occurred often enough in bioethics that a sense of dissatisfaction with the autonomy paradigm is being expressed with increasing conviction and feeling. <sup>83</sup> We may thus be reaching the stage when "[t]he proliferation of competing articulations, the willingness to try anything, the expression of explicit discontent, the recourse to philosophy and to debate over fundamentals [mark] a transition from normal to extraordinary research." <sup>84</sup>

In this paper, then, I want to begin to identify a few of the anomalies and discontents that have arisen out of the work of normal science under the autonomy paradigm. I will do so by examining one challenging kind of empirical evidence about how people actually think about their role in making medical decisions. To that evidence we now turn.

### III. THE EMPIRICAL EVIDENCE

To history has been assigned the office of judging the past, of instructing the present for the benefit of future ages. To such high offices this work does not aspire: It wants only to show what actually happened.

Leopold von Ranke

*Histories of the Latin and Teutonic Nations (1494-1514)*

Given bioethics' autonomy paradigm and its hyper-rational premises—particularly its presumptions that people behave in generally similar

in thinking about the authority of the patient. And there are many countries—even highly industrialized countries—where a very different paradigm presides.

82. KUHN, *supra* note 46, at 52.

83. Among the criticisms particularly noticed have been, for example, Daniel Callahan, *Autonomy: A Moral Good, Not a Moral Obsession*, HASTINGS CENTER REP., Oct. 1984, at 40; Daniel Callahan, *Contemporary Biomedical Ethics*, 302 NEW ENG. J. MED. 1228 (1980); Willard Gaylin, *Autonomy, Paternalism, and Community*, HASTINGS CENTER REP., Oct. 1984, at 5; Robert M. Veatch, *Autonomy's Temporary Triumph*, HASTINGS CENTER REP., Oct. 1984, at 38. I have expressed my own discomforts at misuses of the principle of autonomy in the law of bioethics in *Rights Discourse*, *supra* note 81.

84. KUHN, *supra* note 46, at 91.

ways, that they seek to maximize their autonomy, and that they make decisions by assembling all the relevant data and selecting the course that optimizes the goals they have already developed—it is not surprising that bioethicists and lawyers widely assume that patients want to seize and make their own medical decisions.<sup>85</sup> In light of these assumptions, perhaps some of the most arresting empirical data so far accumulated are those which suggest that a significant number of patients are reluctant to make such decisions. Because this literature is complex and, to hyper-rationalists, counter-intuitive, I will discuss several studies in some detail.

We begin with Ende and his colleagues. They presented 312 patients in a primary-care clinic of a teaching hospital with vignettes representing various levels of illness severity.<sup>86</sup> “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  $33.2 \pm 12.6$ .”<sup>87</sup> Thus, the authors concluded that “patients’ preferences for decision making in general were weak. Moreover, as patients were asked to consider increasingly severe illnesses, their desires to make decisions themselves declined.”<sup>88</sup> Like a number of other studies, this one found that younger people were most likely to want to participate in decisions. More clearly than other studies, this one concluded that higher education, higher occupational status, and being divorced or separated were also associated with such a desire. However, these factors accounted for only 19% of the variation among patients.

This study did very much resemble other studies in one consequential respect: That patients were not avid to participate in decisions did not mean that they did not want to be informed about what was going on. Quite the contrary. Like patients in study after study, these patients widely said they were anxious to be told about their medical situation. In fact, “the mean score for information seeking was  $79.5 \pm 11.5$ .”<sup>89</sup>

Another striking study was conducted by Strull and his associates. They studied 210 hypertension patients and their physicians in a community hospital

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85. Katz, for example, writes, “I said more, although still not enough, about the prevalent assertion that patients generally do not wish to share the burdens of decision and that they prefer instead to trust their doctors’ recommendations blindly. I doubt this assertion.” KATZ, *supra* note 7, at 228. (Of course, in the tendentious way Katz phrases this “prevalent assertion,” it is indeed dubious. I too doubt that patients want to trust their doctors “blindly.”) The President’s Commission comfortably concluded that “the vast majority of people surveyed by the Commission felt that patients . . . ought to participate in decisions regarding their health care.” 1 President’s Comm., *supra* note 58, at 17. For a more exact description of these survey data, see *infra* text accompanying notes 117-19.

86. Jack Ende et al., *Measuring Patients’ Desire for Autonomy: Decision Making and Information-Seeking Preferences Among Medical Patients*, 4 J. GEN. INTERNAL MED. 23, 23 (1989). “Upper respiratory tract illness (URI) represented mild disease; hypertension (HBP), moderate disease; and myocardial infarction (MI), severe or most threatening disease.” *Id.*

87. *Id.* at 25. These results were confirmed in a study of the membership of an HMO. Suzanne C. Thompson et al., *Preferences for Involvement in Medical Decision Making: Situational and Demographic Influences*, 22 PATIENT EDUC. & COUNSELING, 133 (1993).

88. Ende et al., *supra* note 86, at 26-27.

89. *Id.* at 26.

clinic, an HMO, and a VA outpatient clinic.<sup>90</sup> Like the Ende group, they found that patients wanted information. "Fifty-two percent of patients reported that they had received 'quite a lot' of information or 'all there is to know' about hypertension and its therapy from their current clinician."<sup>91</sup> In evaluating the information they had received, "[f]orty-one percent of the patients stated they would have preferred additional information, while 58% received the 'right amount,' and only one patient preferred less information."<sup>92</sup>

But much as the patients wanted to be informed they did not equivalently want to participate in medical 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 . . . . One third of the patients 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.<sup>93</sup>

Intriguingly, the doctors over-estimated their 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."<sup>94</sup>

The patients and physicians disagreed about how decisions were in fact made.

Sixty-three percent of patients reported that the "clinician usually makes the decision, using all that's known about the medicines," while clinicians reported such decision making in only 20% of cases . . . . Only 37% of patients, as opposed to 80% of clinicians, reported that the patient participates to any extent in decisions.<sup>95</sup>

But whatever was happening was not making the patients unhappy. Eighty-nine percent of them "reported being 'very' or 'extremely' satisfied with their overall medical care from their current clinician, and 84% reported a 'very' or 'extremely' high degree of satisfaction with the way in which decisions about their treatment are made."<sup>96</sup>

Vertinsky and his collaborators also studied a population whose interest in being informed exceeded their interest in controlling their treatment.<sup>97</sup> This

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

91. *Id.* at 2991. The clinicians, however, "reported giving these amounts of information in only 38% of cases." *Id.*

92. *Id.*

93. *Id.* at 2992 (quoting the language used on a questionnaire to patients).

94. *Id.*

95. *Id.*

96. *Id.* at 2993.

97. Ilan B. Vertinsky et al., *Measuring Consumer Desire for Participation in Clinical Decision Making*, 9 HEALTH SERV. RESEARCH 121 (1974).

team surveyed two hundred randomly chosen residents of Vancouver and asked them how they would react to a scenario in which a patient has a strep throat and in which the doctor does not tell the patient all the risks of either non-treatment or treatment. The factor that was least often chosen was "patient decision," which was "defined in terms of preference for retaining the final decision function in the patient's hands."<sup>98</sup> Indeed, "[d]irect participation ('Patient Decision') . . . was rated as unimportant by almost all subjects, although patients indicate rather strongly a desire to maintain some measure of participation ('Avoidance' receiving markedly low scores)."<sup>99</sup>

Another study showing that a substantial number of patients are loath to make their own medical decisions was conducted by Faden and her co-workers.<sup>100</sup> They asked 53 seizure patients to choose between, on one hand, having their doctor decide whether they needed medication and, if so, which medication or, on the other hand, hearing the doctor's recommendation but deciding whether to receive medication and which to take. The former course was chosen by 44.2%, the latter by 55.8%.<sup>101</sup> Thus while a majority of the patients questioned preferred to make their own medical decision, a very large minority rejected that approach. This result is particularly remarkable because the patients studied (who were from Walter Reed Hospital) "could be described as young, adult, married, white and fairly well educated,"<sup>102</sup> a selection of people probably likeliest to want to make their own medical decisions.

Beisecker studied 106 people "with a wide range of ailments and disabilities: recovering stroke patients, head trauma and other accident victims, patients with sports injuries, amputees, and patients with severe arthritis, chronic back pain, and muscle diseases such as muscular dystrophy" who were patients of specialists in physical medicine and rehabilitation.<sup>103</sup> Beisecker used a scale for measuring preferences about medical decisions on which "belief in the patient as sole locus of decision-making authority would yield a scale score of 26; belief in the doctor as the sole decision-maker would yield a score of 0, and belief that all decisions should be made jointly (or indicating that a doctor's decisions counterbalanced those which should

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98. *Id.* at 128. This factor was comprised of statements like: "Ask the doctor to give him all the information he has, and then the patient decides what to do." *Id.*

99. *Id.* at 133. Avoidance was "defined in terms of items indicating propensity to delegate the decision function completely (□ 'Just follow the doctor's orders and go home')." *Id.* at 128.

100. Ruth R. Faden et al., *Disclosure of Information to Patients in Medical Care*, 19 MED. CARE 718 (1981).

101. What makes the study particularly interesting was that 93% of the neurologists interviewed believed the doctor should make the choices. However here, as in a number of other efforts, the usefulness of the study's results are impeded by the fact that its respondents were forced to choose between only two options. Once again, too, the study reported extremely widespread interest in information about available medications and their risks. Interestingly, though, the information the fewest people wanted was the information about "drug-related mortality."

102. Faden et al., *supra* note 100, at 720.

103. Analee E. Beisecker, *Aging and the Desire for Information and Input in Medical Decisions: Patient Consumerism in Medical Encounters*, 28 GERONTOLOGIST 330, 332 (1988).

be made by the patient) would yield a score of 13."<sup>104</sup> The mean score for Beisecker's medically diverse population was 8.6.

Mark and Spiro studied 102 outpatients scheduled to undergo a colonoscopy. "When asked, 'Which way would you prefer to come to a medical decision?' 57 patients wanted to share the decision with the physician, 22 wanted to make their own decision, and 23 wanted the physician to make the decision."<sup>105</sup> Asked about the decision to have a colonoscopy examination, "53 patients said that they shared the decision with the physician, 40 patients said that the physician was most responsible for the decision, and 9 patients said that they were most responsible." Yet despite the apparent discrepancy between how some patients said they wanted medical decisions to be made and the way the colonoscopy decision was made, "only two patients declined to say in the end that they had 'just the right amount of responsibility in making the decision . . .'"<sup>106</sup>

A study by Lidz and his collaborators of informed consent produced clearer results.<sup>107</sup> They concluded that, "with a few exceptions . . . , the patients believed that decisions about their treatment should be primarily or completely up to their physicians because of their technical expertise and commitment to the best interests of the patients."<sup>108</sup> Again, patients did want information. But "[o]nly about 10% of the patients we interviewed saw themselves as having an active role in decision making."<sup>109</sup>

Also notable, if rather vaguely reported, is a study by Miller, et al., of 150 primary-care patients at a department of internal medicine. This study was undertaken to evaluate the way different personality types respond to threats to their health. It found that "almost no patients desired to have the final say in their medical care" and that 36.5% of one personality type and 15.9% of the other "desired to play a completely passive role in their own care."<sup>110</sup>

An illuminating perspective on the desire of patients to make medical decisions comes from a study by Degner and Sloan, whose study compares the attitudes of newly diagnosed cancer patients and a random sample of residents of Winnipeg.<sup>111</sup>

104. *Id.*

105. Jennifer Susan Mark & Howard Spiro, *Informed Consent for Colonoscopy*, 150 ARCHIVES OF INTERNAL MEDICINE 777, 777-78 (1990).

106. *Id.* at 778.

107. Charles W. Lidz et al., *Barriers to Informed Consent*, 99 ANNALS INTERNAL MED. 539 (1983). One more impressionistic study of informed consent reported that the researcher's "period of observation bore out that in many cases patients do request or allow physicians to make decisions for them." Jones, *supra* note 4, at 419-20 (citation omitted).

108. Lidz et al., *supra* note 107, at 540.

109. *Id.* at 541.

110. Suzanne M. Miller et al., *Styles of Coping with Threat: Implications for Health*, 54 J. PERSONALITY & SOC. PSYCHOL. 142, 146 (1988). They found that 48.1% of the former personality type ("high monitors") and 71.4% of the latter ("low monitors") "preferred that treatment decisions be made jointly by themselves and their physicians." *Id.*

111. Lesley F. Degner & Jeffrey A. Sloan, *Decision Making During Serious Illness: What Role Do Patients Really Want to Play?*, 45 J. CLINICAL EPIDEMIOLOGY 941 (1992).

The majority of newly diagnosed patients (59%) preferred that physicians make treatment decisions on their behalf. The most popular first choice of patients was the statement, "I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion." Only 12% of newly diagnosed patients preferred to play an active role in decision making.<sup>112</sup>

The residents of Winnipeg, in contrast, seemed more interested in such participation. Sixty-four percent of them thought they would want to play an active role in decision making if they were to develop cancer.<sup>113</sup>

Another Canadian study questioned 52 cancer patients in early stages of their disease.<sup>114</sup> Sixty-three percent of them "felt the physician should take the primary responsibility in decision making, 27% felt it should be an equally shared process, and 10% felt they should take a major role."<sup>115</sup> Again, even patients who expected their doctors to assume the primary responsibility for medical decisions were interested in receiving information.

Another relevant study was conducted by Cassileth and company.<sup>116</sup> They gave 256 cancer patients a choice between two statements: "I prefer to participate in decisions about my medical care and treatment," and "I prefer to leave decisions about my medical care and treatment up to my doctor." Eighty-seven percent of those aged 20 - 39, 62% of those aged 40 - 59, and 51% of those over 60 chose the former statement.<sup>117</sup> This is one of the most frequently recruited citations for the proposition that patients *want* to make medical decisions. Yet even it concludes that a substantial number of patients are willing to subscribe to quite a strongly stated desire to cede authority to their doctors. In addition, the reaction to this study typifies a common but unfortunate response to empirical studies—to transform a finding that a majority prefer something into the assertion that everyone wants it. As has been well said, "In health index construction, in the evaluation of the outcomes of clinical trials and in clinical decision analysis for groups of patients the use of average preference scores runs the danger of 'the tyranny of the majority': it essentially disregards the opinions of those whose scores are removed from the mean."<sup>118</sup>

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112. *Id.* at 945-46.

113. *Id.* at 946. Once again, age was the best (though not a particularly strong) predictor of a preference for participation in making decisions. Interestingly, "[t]he clinical hypothesis that patients who are more ill prefer less control in cancer treatment decision making was not supported. Neither symptom distress levels nor stage of disease were related to patients' role preferences." *Id.* at 947.

114. H.J. Sutherland et al., *Cancer Patients: Their Desire for Information and Participation in Treatment Decisions*, 82 J. ROYAL SOC'Y MED. 260 (1989).

115. *Id.* at 262.

116. Barrie R. Cassileth et al., *Information and Participation Preferences Among Cancer Patients*, 92 ANNALS INTERNAL MED. 832 (1980).

117. *Id.* at 834. Once again, the desire for information outweighed the desire for control: The parallel assents to the statement "I want as *much* information as possible, good and bad" were 96%, 79%, and 80%. *Id.* at 833-34 (emphasis in original).

118. Health Services Research Group, *Studying Patients' Preferences in Health Care Decision Making*, 147 CAN. MED. ASS'N J. 859, 862 (1992).

Furthermore, even those who chose the first of the two statements in the Cassileth study were only asking for *some*—unspecified—level of participation in decisions. Some, and perhaps many, of those patients may have wanted little more than to receive good information and to retain a veto power over their doctor's decisions (although presumably others of them actually wanted to make some decisions in some stronger sense). In addition, it seems likely that the *relatively* great desire for participation this study reports is an artifact of the maximally narrow range of choices the respondents were given.<sup>119</sup>

Finally, there is the Louis Harris poll of doctors and the general public undertaken for the President's Commission.<sup>120</sup> Seven percent of the public wanted the doctor to present all the possible alternatives and to let the patient decide. Twelve percent wanted the doctor to present a recommendation for the patient to accept or reject. Seven percent wanted the doctor to decide what should be done and to do it. Seventy-two percent thought the doctor should discuss alternatives with the patient and that they should then decide together what to do. Less than half a percent thought the way to proceed depends on the circumstances.<sup>121</sup>

This is probably the strongest statement of a public desire to make medical decisions. However, it is not easy to interpret. Most of the respondents wanted the doctor and patient to decide together what to do, but it is most unclear just how they envisioned the allocation of power between the doctor and patient. For instance, Ende and his colleagues conclude that the Harris data "seem to support the notion that patients prefer the model wherein the doctor keeps the patient informed and engages the patient in the decision making process, rather than having the patient function as the principal decision maker."<sup>122</sup> It is at least significant that very few patients opted for the response—having the doctor present alternatives for the patient's decision—that comes closest to Brock's formulation of the autonomy standard for patients' decisions.

What, then, can we say of the studies of patients' desires to participate in medical decisions? They certainly have their drawbacks. To begin with, they

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119. For criticisms of this feature of the Cassileth study, see Degner & Sloan, *supra* note 111, at 948; Ende et al., *supra* note 86, at 27. Other studies have used the same two-alternatives question about decision-making employed in the Cassileth study and have yielded relatively high desires to make decisions, although still with substantial numbers preferring to avoid decisions. For example, one study reported that 70% of their respondents wanted to participate in medical decisions. Marc D. Silverstein et al., *Amyotrophic Lateral Sclerosis and Life-Sustaining Therapy: Patients' Desires for Information, Participation in Decision Making, and Life-Sustaining Therapy*, 66 MAYO CLINIC PROC. 906, 908 (1991). Similarly, Christina G. Blanchard et al., *Information and Decision-Making Preferences of Hospitalized Adult Cancer Patients*, 27 SOC. SCI. MED. 1139, 1143 (1988), found that "almost one-third (30.5%) [of the cancer patients they interviewed] stated that they preferred to leave decisions about their medical care and treatment up to their doctor."

120. Louis Harris & Associates, *Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public*, in 2 President's Comm., *supra* note 58, at 17.

121. *Id.* at 209. It is also notable that the worse the health of the respondents, the less likely they were to want to make their own decisions.

122. Ende et al., *supra* note 86, at 27. For a useful attempt to demonstrate that all the studies showing a higher desire for participation do not conflict with the conclusions of those studies showing a lower desire, see *id.* at 27-28.

generally used questions which were frustratingly inexact, so that we are almost always left to guess precisely what allocation of authority the respondents had in mind. Part of the problem here is due to the fact that all the studies I have reviewed are quantitative surveys, not the kind of qualitative, ethnographic research that might better yield more richly textured information. Thus these studies do disappointingly little to dispel the haze of imprecision veiling discussions of how authority should be allocated between patient and doctor.

Further, there are reasons to have some qualms about the reliability of the enterprise of asking people what role they want in medical decisions. People will quite reasonably not always know what they want. These are, after all, hard questions and questions about which many people will not have thought much and about which people may change their minds with experience and reflection. Indeed, these are questions about which people may reasonably be primarily ambivalent. And even people who know what they want will often have difficulty articulating their preferences. All these problems are at their most acute when, as often occurred, studies ask people who are not sick to speculate about how they would feel about medical decisions if they were sick, or ask people who are sick about hypothetical variations on their illness. Along these lines, it is tantalizing that none of the studies probes very far—if at all—into the *reasons* people might have for wanting or rejecting medical authority. That information might have helped us understand much more accurately what patients truly want.

In addition, these studies do not adequately take into account the daunting range of circumstances in which medical decisions are made. It will surely matter how sick or healthy the patient is, how well the doctor and patient know each other, how trivial or consequential the decision is, how technical the issues raised, and so on. It will particularly matter where the decision falls on the (somewhat artificial) continuum between purely medical decisions on one hand and purely social or moral decisions on the other.

Nevertheless, these studies are the best evidence we have about peoples' attitudes toward medical decisions. And I believe they are adequate to provide a basis for thinking about those attitudes. Taken as a whole, these studies surveyed a considerable variety of populations—from the perfectly well to the dangerously sick. They asked patients about their own conditions and about hypothetical illnesses. They framed their respondents' choices in a variety of ways. And their virtually universal conclusion was that, while patients commonly wish to be informed about their medical circumstances, at least a quite substantial number of them did not want to make their own medical decisions, or perhaps even to participate in those decisions in any very significant way.

Another reason for taking these studies seriously is that their conclusions about people's reluctance to seize control of their medical decisions find some substantiation in several different kinds of evidence. Consider, first, the reaction to the burgeoning availability of advance directives. In recent years,



cases like *Quinlan*<sup>123</sup> and *Cruzan*,<sup>124</sup> publicists like Jack Kevorkian, and referenda like those in Washington and California have brought questions about terminating life support to the fore of public discussion. Part of this discussion has consisted of adjurations to sign advance directives. That people should do so has become the conventional wisdom. Patients have forms thrust upon them when they enter health-care facilities. Many lawyers routinely offer to prepare advance directives when people come in for estate planning. Despite all this, relatively few people have prepared advance directives, and many people appear reluctant to discuss such matters even with their families (to say nothing of their doctors).<sup>125</sup> There are, to be sure, a number of reasons for this, not least that people are fearful and superstitious, that they "prefer to avoid the subject of how to manage their own dying."<sup>126</sup> But the point is exactly that many people have strong reasons for not wanting to grasp the nettle of autonomy.

Much more arresting is the evidence that people do not necessarily contemplate that advance directives should necessarily be scrupulously followed. In a study conducted by Sehgal and her colleagues, 150 dialysis patients were asked "[w]hom they would want to help their physician make decisions for them if they developed advanced Alzheimer's disease" and "[h]ow much leeway their physician and surrogate should have to override this advance directive if overriding were in their best interests."<sup>127</sup> These patients "varied greatly in how much leeway they would give their physician and surrogate to override their advance directive if overriding were in their best interests: 'no leeway' (39%), 'a little leeway' (19%), 'a lot of leeway' (11%), and 'complete leeway' (31%)."<sup>128</sup> In brief, if people were as avid to

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123. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

124. *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).

125. For instance, Caplan concludes that no more than 10% of the population has an advance directive. *Can Autonomy Be Saved?*, *supra* note 26, at 261. It appears that even those presumptively most in need of advance directives prepare them with surprising infrequency. Thus one study found that, while half of the 39 nursing home patients questioned had thought about end-of-life decisions, only 6 had actually signed advance directives. Eric L. Diamond et al., *Decision-Making Ability and Advance Directive Preferences in Nursing Home Patients and Their Proxies*, 29 GERONTOLOGIST 622 (1989). One random survey of outpatients found that only 11% had discussed cardiopulmonary resuscitation with their doctors, while 67% had thought of doing so. (Forty-four percent had discussed the issue with someone else.) Mark H. Ebell et al., *The Do-Not-Resuscitate Order: Outpatient Experience and Decision-Making*, 31 J. FAM. PRAC. 630 (1990). Another study found that only 9% of its respondents had discussed surrogate decision-makers with their doctors and that only 6% had discussed life-sustaining treatment. Bernard Lo et al., *Patient Attitudes to Discussing Life-Sustaining Treatment*, 146 ARCHIVES INTERNAL MED. 1613 (1986). For a review of studies suggesting that people rarely discuss termination of treatment with either their families or their doctors, see Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients*, 267 JAMA 2067, 2068-69 (1992).

126. *Can Autonomy Be Saved?*, *supra* note 26, at 263. Caplan observes that there has been a similar reluctance to sign organ-donor cards.

127. Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 JAMA 59, 60 (1992).

128. *Id.* at 61. "Sixty percent of subjects with prior written directives wanted advance directives followed strictly in our scenarios. By contrast, 33% of subjects without prior written directives wanted advance directives followed strictly . . ." *Id.* People with histories of other serious illness (cancer or stroke) were particularly unlikely to want their advance directives strictly followed. *Id.* For reflections on this problem, see Dan W. Brock, *Trumping Advance Directives*, HASTINGS CENTER REP., Sept.-Oct.

make their own medical decisions as is supposed, would they not more eagerly seize the opportunity to make advance directives, and would they not more consistently oppose meddling with directives they had made?

Another behavioral datum likewise hints that patients hesitate about taking control of medical decisions. One might suppose that if patients were ever to assert their decisional authority, it would be after hearing the alarming recitation of risks that characterizes the process of informed consent. Yet a number of studies of that process "strongly suggest that refusals attributable to disclosures are rarely, if ever, seen."<sup>129</sup> Similarly, a study of why patients refuse treatment found an average of 4.6 refusals per 100 patient days.<sup>130</sup> The reasons for refusal were complex, and generally there was more than one "cause" per patient. But two kinds of reasons stood out: first, a failure to tell the patient about the purpose of what was proposed; second, psychological factors, prominently including "characterological factors" (for example, using a refusal to accept treatment as a way of expressing a wish to be cared for) and "other psychoses." While the first of these causes reconfirms the wish for information we have so frequently encountered, neither of them is inconsistent with a reluctance to take control of medical decisions.<sup>131</sup> And the dog that did not bark in the night is the absence of any significant number of patients who heard a doctor's recommendation and reached a different decision on the merits.<sup>132</sup>

Yet another piece of evidence about the reluctance of some patients to assume the reins of medical command comes from my own research. The doctors I have so far interviewed—and I hasten to say my interviews are far from complete and can hardly claim to be either fully representative or systematic—agree emphatically that a significant number of patients do not want to make their own medical decisions.<sup>133</sup> To be sure, these doctors may

1991, at 55.

129. Faden et al., *supra* note 100, at 732. Similarly, "the empirical and anecdotal studies of patients who refuse treatment almost never portray the process of obtaining informed consent as playing a causative role." APPELBAUM ET AL., *supra* note 4, at 202.

130. Paul S. Appelbaum & Loren H. Roth, *Patients Who Refuse Treatment in Medical Hospitals*, 250 JAMA 1296, 1297 (1983). The Harris Report observes that 79% of all those surveyed reported that they had never refused treatment a doctor recommended. The report does not reveal what kind of treatment the other 21% refused or why they refused it. 3 President's Comm., *supra* note 58, at 184 app. B.

131. As Sherlock puts the point, "[e]ven when patients refuse recommended treatment, they do so usually not for elaborate reasons of religious or moral principle but most often because they have lost the trust essential for care, i.e., they do not believe the physician or the staff cares for them and they can no longer entrust their care to these persons." Richard Sherlock, *Reasonable Men and Sick Human Beings*, 80 AM. J. MED. 2, 3 (1986). Perhaps the widespread phenomenon of patient "non-compliance" represents a kind of passive resistance to the doctor's making of medical decisions. I suspect, however, that it at least represents a good deal more as well.

132. Of course, there are good reasons not to expect massive patient refusals after being given "informed consent." Informed consent often comes rather late in the decision-making process, doctors often do not take it as seriously as courts wish, doctors can frame information to make the recommended choice relatively attractive, and so on. But the virtual absence of patient refusals at that point is too complete a phenomenon to be accounted for just in terms of the defects of informed consent.

133. Katz (disapprovingly) quotes Richard Selzer in a somewhat hyperbolic version of such physicians' reports: "When I try to call the patient in on a consultation and say, 'Which alternative would you prefer?' invariably the patient says, 'What do you mean, which alternative? I want you to

have their own reasons for believing and saying that patients want to cede them authority, and they are guided by their own cultural preconceptions when they interpret what patients do and say. But I am as reluctant to dismiss their evidence entirely on those grounds as I am to dismiss the assertions of bioethicists and lawyers because of their own considerable stakes—economic, social, and intellectual—in the issues they debate. And, to be sure, doctors have notorious difficulty assessing their patients' desire to make medical decisions.<sup>134</sup> But doctors have a unique and rich perspective and experience too valuable to be lost and too direct to be dismissed out of hand. Thus, I believe that the testimony of these doctors is at least relevant as confirmation of what the other sources I have reviewed indicate.

A final confirmation of my thesis—anecdotal but illuminating—comes from the memoirs of the sick and of the families who have cared for them. Some of these memoirists complain of being deprived of decisional authority.<sup>135</sup> But a number—I would say a preponderance—of these extensive and intensive accounts of sickness conspicuously fail to make that complaint.<sup>136</sup> The self-conscious and articulate folk who write these memoirs are exactly the people one would think likeliest to want such authority and to notice and criticize its absence. They are certainly willing to express their unhappiness, even their bitterness, with other medical deficiencies. But their grievances have most conspicuously to do not with being deprived of authority, but with medical errors, with doctors' lack of sympathy and understanding, with lack of information, with the insolence and inefficiencies of medical bureaucracy, and with doctors who were not there to attend to the case. (And, it should be said, these same memoirists often volunteer appreciation and even enthusiasm for doctors who were conscientious, kind, and competent.)

This anecdotal evidence finds some (rather tangential) substantiation in two kinds of empirical data. The first kind lies in studies of what causes dissatisfied patients to sue their physicians. One such study found that "while the current trend in medicine stresses the importance of treating patients as

tell me what to do. You're the doctor." KATZ, *supra* note 7, at 126 (quoting F. Middleton, *Profile: Richard Selzer*, NEW HAVEN MAG., July 1983, at 37).

134. See, e.g., Strull et al., *supra* note 90, at 2992.

135. See, e.g., MARTHA WEINMAN LEAR, HEARTSOUNDS (1980); ANDREW H. MALCOLM, SOMEDAY: THE STORY OF A MOTHER AND HER SON (1991); CORNELIUS RYAN & KATHRYN MORGAN RYAN, A PRIVATE BATTLE (1979). Cornelius Ryan, the author of several books on World War II battles, resolved to research his disease in the same way that he researched those battles. Malcolm's book is an argument in favor of allowing patients more control of the decision to end treatment necessary to keep them alive. Lear's husband died of heart disease. With Ryan he is the patient in these memoirs most anxious to control his own treatment. Notably, he was also a physician. Lear herself, however, exclaims at one point of a conversation with one of her husband's doctors, "Damn, don't give me options. Give me guidance." LEAR, *supra* at 291.

136. E.g., ANATOLE BROYARD, INTOXICATED BY MY ILLNESS, AND OTHER WRITINGS ON LIFE AND DEATH (1992); ARTHUR W. FRANK, AT THE WILL OF THE BODY (1991); MOLLY HASKELL, LOVE AND OTHER INFECTIOUS DISEASES: A MEMOIR (1990); BERNICE KAVINOKY, VOYAGE AND RETURN (1966); MADELEINE L'ENGLE, TWO-PART INVENTION: THE STORY OF A MARRIAGE (1988); FITZHUGH MULLAN, VITAL SIGNS: A YOUNG DOCTOR'S STRUGGLE WITH CANCER (1983); ROBERT F. MURPHY, THE BODY SILENT (1990); PHILIP ROTH, PATRIMONY: A TRUE STORY (1991); OLIVER SACKS, A LEG TO STAND ON (1987); BARBARA D. WEBSTER, ALL OF A PIECE: A LIFE WITH MULTIPLE SCLEROSIS (1989).

active participants in the delivery of medical services, such considerations may have few consequences for disputing. At bottom, only the doctor's perceived competence and attention to the patient's health appear to influence the decision to sue.<sup>137</sup> The second kind of support for the conclusion I have drawn from patients' and families' memoirs comes from studies of patient satisfaction. These studies commonly conclude that patients are generally satisfied with the care they receive from their own physicians (even if they are not so content with doctors *en masse*) and with their degree of participation in medical decisions.<sup>138</sup>

In sum, not only does the survey literature strongly suggest that a significant number of people do not yearn to make their own medical decisions, but that literature is substantiated—sometimes obliquely, sometimes directly—by a variety of other kinds of evidence. But one other point about this body of evidence needs to be recognized. There is reason to think that the graver the decision, the less likely the patient may be (other things being equal) to want to address it. There is, in other words, evidence that the more severe the patient's illness, the less likely the patient is to want to make medical decisions.<sup>139</sup> This is plausible enough, since the sicker a patient is, the less energy and capacity the patient is likely to feel. If this is true, it is important, since it means that the most consequential decisions will often be exactly those the patient is the least inclined to make.

Similarly, as we have seen, there is fairly consistent evidence that the older patients are, the less likely they are to want to make their own decisions. This is also important, and for much the same reason: those patients who are likeliest to have serious medical problems and to be making life-and-death decisions are least likely to relish making their own decisions. Thus, the survey data may even understate the extent to which actual patients with serious decisions to make want to exercise their autonomy.

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137. Marlynn L. May & Daniel B. Stengel, *Who Sues Their Doctors? How Patients Handle Medical Grievances*, 24 L. & SOC'Y REV. 105, 116 (1990). Their results "tentatively suggest that patients are not affected by many of the procedural niceties of these efforts [to improve communication between doctor and patient]: involving the patient as partner, informing the patient about care, not rushing the patient's visit, and taking personal care about the patient's medical problem." *Id.* at 118.

138. As the President's Commission noted, its survey found that "only 7% of the public reports dissatisfaction with their doctors' respect for their treatment preferences." PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP, VOLUME ONE: REPORT 46 (U.S. G.P.O. 1982). To like effect, see, e.g., Mark & Spiro, *supra* note 105, at 778; William M. Strull et al., *Do Patients Want to Participate in Medical Decision Making?*, 252 JAMA 2990, 2993 (1984).

139. Ende et al., *supra* note 86, at 26-27; Harris & Associates, *supra* note 120, at 17; Sutherland et al., *supra* note 114, at 260. Similarly, another study found that patients "who preferred leaving decisions to the physician had a lower performance status, i.e., in bed more than half of the day or totally bedridden, than those who preferred to participate in decisions . . ." Blanchard et al., *supra* note 119, at 1142. And it is highly suggestive that older people, who have generally had more experience with serious illness than young people, are also likelier to wish to defer their medical decisions to someone else. See, e.g., Cassileth et al., *supra* note 116. It is also suggestive that people with histories of serious illness were particularly unlikely to be anxious that their advance directives be strictly followed. *But cf.* Degner & Sloan, *supra* note 111, at 947 (finding that symptom-distress levels were not related to patients' preferences about decisions).

The evidence I have been summarizing is highly suggestive but hardly unequivocal. The studies I have reviewed differ markedly in their quality, in their range, in their goals, in their sites, in their patient populations, in their techniques, in their results, and in their conclusions. Taken as a whole, the evidence I have amassed leaves many questions unanswered. It resembles the few, damaged, and scattered stones in an ancient mosaic discovered by an archeologist. They establish convincingly enough the subject of the picture; but they leave its details uncertain.

This evidence, for instance, indicates quite clearly that most patients believe they want "information." But it hardly tells us which kinds of information patients want, how much of it they want, when they want it, why they want it, when they might not want it, or what they might do with it. For example, in my own research I interviewed one patient who distinctly wanted to be kept informed of what was going to happen next, but did not want to be told until right before it was going to happen, since he did not want to dwell on possibly unpleasant information that he did not immediately need. Many other patients I have talked with seem much more anxious for information that will be helpful in handling day-to-day problems than in hardcore medical information. And so on.

In addition, the evidence I have reviewed tells us that many, but not all, and perhaps not even most, patients are reluctant to assume full decisional power. But much remains unclear. That patients do not want full power does not mean that they want none. It seems likely, for instance, that even patients who wish to yield authority to make most decisions wish to retain residual authority to countermand particularly troublesome ones. It is at least apparent that patients do want a good deal of information, and information permits patients to oversee their treatment to some extent and to intervene in it if they so choose.

That patients want to cede some of their authority does not tell us to whom they wish to cede it. It seems likely, for example, that some patients want to accord some of their authority not to their doctors but rather to their families. I have encountered a number of examples of this in my research. Quite often, one will see elderly but competent parents who have effectively delegated authority to make medical decisions to their middle-aged children. And not infrequently one encounters similar delegations one spouse has made to the other.<sup>140</sup>

Further, that patients do not relish making "medical" decisions does not mean that they are similarly reluctant to make social or moral decisions raised by their illness. Thus a patient might refuse to make any decision about what kinds of treatment to receive, but might insist on retaining the power to reject some treatments as socially impractical or even to reject treatment altogether.

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140. For reflections on the role of families in medical decisions, see Jeffrey Blustein, *The Family in Medical Decisionmaking*, HASTINGS CENTER REP., May-June 1993, at 6; Symposium, *Ethics, Bioethics, and Family Law*, 1992 UTAH L. REV. 735. For an extended and moving description of the way one son shared decisional authority with his father, see ROTH, *supra* note 136.

In sum, the empirical evidence I have recited raises many provocative issues and suggests many fascinating questions for future inquiry. That is part of the attraction of these data and of the empirical method in bioethics. But these studies seem to me quite strong enough to support at least one telling conclusion: A significant—and perhaps quite a substantial—number of people are not hungry to make decisions about their medical problems.

### CONCLUSION

No themes are so human as those that reflect for us, out of confusion of life, the close connexion of bliss and bale, of things that help with the things that hurt, so dangling before for ever that bright hard medal, of so strange an alloy, one of which is somebody's right and ease and the other pain and wrong.

Henry James  
*What Maisie Knew*

What are we to make of the data I have reviewed? As I hope I need not say, those data do not show, and are not recruited to show, that autonomy is a valueless value, that many patients do not want to exercise it in many ways, or that the law should discard autonomy from its agenda of esteem. But these data seem to me to exemplify the ways in which empirical research can raise fruitful questions about the scope, strength, and nature of the autonomy paradigm. I believe, in other words, that we have at least reached that point in the Kuhnian progression at which we need to develop and refine the autonomy paradigm to take into account the world's complexity, to accord each element of the paradigm a better-gauged place, to accommodate competing claims and interests. The data I have surveyed raise questions which will help us in those tasks.

What are some of those questions? First, why do so many patients say they do not want to make their own medical decisions? Is the autonomy paradigm correct in tacitly assuming that people in fact, at base, truly do want to make their own medical decisions? Have the patients who say they do not want to make medical decisions been seduced into misunderstanding their own preferences? Have the structure of medicine and the arrogance of doctors deprived patients of even the will to claim their rightful authority over their own decisions? Or, on the other hand, can patients have any substantial and persuasive reasons for wishing to delegate authority over medical decisions to their doctors, their families, or their friends?

What, to take a more specific example of a useful question, is the relationship between the common perception that people generally want to "control" their own lives and the evidence that some patients are not anxious to make their own medical decisions? Is that perception correct? Is making one's own medical decisions the best way of asserting control? What do people mean by control? Is control possible?

The data I have surveyed should also lead us to ask whether we have framed our questions properly. Bioethics and the law tend to talk about medical decisions as though they were sufficiently alike to constitute a single category. But might we be well advised to disaggregate that category? Are all the decisions we put in it actually medical decisions, as opposed to moral, religious, or social decisions? Do patients have any pressing need or technical competence to make all the choices that are genuinely "medical" decisions? Can we devise more precise categories of questions to fit the probably wide range of dilemmas we now describe as "medical questions"?

The data I have surveyed raise yet another greatly important but insufficiently explored question: To what extent are patients morally obliged to exercise their autonomy whether they want to or not? Patients might reasonably suggest that they are exercising their autonomy by declining to make their own medical decisions. But it might plausibly be said in response that patients have duties—to themselves, to their family and friends, to their medical attendants—to make their own decisions. It might be argued that patients will best discharge their duty to maintain their own health by making their own medical decisions. It might be said that patients should not impose the moral burdens of consequential decisions on other people, that patients have a duty to chart their own life course and to shoulder responsibility for their own welfare.

Finally, these data raise questions about how people who truly do not wish to make their own medical decisions should be treated. How should such patients be identified? How can they be distinguished from patients who say they do not want to make decisions but at some deeper level actually do want to make them? Should patients be encouraged to make medical decisions? Educated to make them? Compelled to make them? More broadly, how should medical decisions be socially structured to take into account the whole range of patient preferences?

In sum, the empirical data I have reviewed in this Article raise a host of problematic and pressing issues, issues which will force us to re-examine the autonomy paradigm and the hyper-rationalist assumptions on which we have allowed it to rest and to temper and deepen it. The reader is entitled to ask what kind of empirical evidence we have about those issues, and how they are best addressed. In a subsequent article, currently titled *Toward New Paradigms for Bioethics: Patients, Doctors, Decisions, and the Practice of Autonomy*, I will soon take on that enterprise.