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LIMPING IS NO SIN: REFLECTIONS ON
MAKING HEALTH CARE DECISIONS

Jay Katz*

INTRODUCTION

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research ("President's Commission" or "Commission"), in its report on Making Health Care Decisions ("Report"),¹ proclaimed its underlying message in memorable words:

[T]he Commission attempts to shift the terms of the discussion toward how to foster a relationship between patients and professionals characterized by mutual participation and respect and by shared decisionmaking. The Commission believes such a shift in focus will do better justice to the realities of health care and to the ethical values underlying the informed consent doctrine.²

Such sentiments constitute a bold move to imprint on physicians, patients, and society the Commission's moral vision of how doctors and patients should make joint decisions in the future.

I have nothing but admiration for the Commission's remarkable vision, which is so contrary to the medical profession's view of how physicians and patients should converse with one another. Being deeply committed to the Commission's vision, I cannot improve on its sentiments. I can expand, however, on the enormity of the task that confronts physicians and patients if the Commission's noble aspirations are to be attained.

The writers of the Report were, of course, aware of the problems I shall discuss, but they did not address them as forthrightly as they deserve to be addressed. Thus, what I have to say should be read as a concurring opinion to a Report that seeks to radically alter traditional patterns of physician-patient decisionmaking.³

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² President's Commission, supra note 1, at 36 (emphasis added).

³ Physicians have always maintained that patients are only in need of caring custody. Doctors felt that in order to accomplish that objective they were obligated to attend to their patients' physical and emotional needs and to do so on their own
In reflecting on the Report, I wondered whether the Commission, aware of the audacity of its objectives, tried to blunt and hide the revolutionary implications of its vision. If I am correct, this is my only criticism of the Report.

The Commission correctly observed "that [its] conclusions . . . will not be simple to achieve." Yet, at the same time, it also asserted "that a number of relatively simple changes in practice could facilitate patient participation in health care decisionmaking." Thus, the Commission appreciated the enormity of the effort that any reasonable implementation of its vision would entail, yet immediately denied this reality by glossing over the current low state of shared physician-patient decisionmaking. This is evidenced by the prominence the Commission gave to the findings of the Harris poll, which painted a rosy picture of the current state of physician-patient decisionmaking. Indeed, if the Harris poll is to be believed, then all is well and a much shorter report would have sufficed, for the Harris poll suggests that the world of the doctor and patient is not as silent as I believe it to be.

The President's Commission should have given greater weight to the observational studies it had also commissioned, particularly to the perceptive studies conducted by Professors Lidz and Meisel. They were correct, I believe, in concluding that:

[1] "Disclosure" does not typically occur. Rather patients learn various bits of information, some relevant to decisionmaking, some not, from doctors' and nurses' efforts to obtain compliance and from "situational etiquette."

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authority, without consulting with their patients about the decisions that needed to be made. Indeed, doctors intuitively believed that such consultations were inimical to good patient care. The idea that patients may also be entitled to liberty, to sharing the burdens of decision with their doctors, was never part of the ethos of medicine.


4 President's Commission, supra note 1, at 6 (emphasis added).

5 Id. at 4 (emphasis added).

6 See, e.g., J. Katz, supra note 3, at 90–103 (The Story of Iphigenia); id. at 131–41 (The First Two Heart Transplant Patients).

7 "Louis Harris and Associates conducted parallel national surveys of physicians and the public regarding their attitudes toward, experiences with, and knowledge of informed consent, disclosure of information, and decisional authority in medical care." 1 President's Commission, supra note 1, at 8. The results of the Harris poll are reproduced in their entirety in 2 President's Commission, supra note 1, at 17–316.

8 See, e.g., infra note 57 and accompanying text.

9 Lidz & Meisel, Informed Consent and the Structure of Medical Care, in 2 President's Commission, supra note 1, at 317–410; Appelbaum & Roth, Treatment Refusal in Medical Hospitals, in 2 President's Commission, supra note 1, at 411–77.

10 Lidz & Meisel, supra note 9.
“Decisions” are not made by patients. “Recommendations” are made by doctors to patients.

“Consent” does not exist. Instead what we find is “acquiescence,” the absence of “objection,” or occasionally a “veto.”

In light of these findings, the results of the Harris poll become suspect, if not irrelevant. By taking the Harris poll seriously and by downgrading the significance of its own observational studies, the Commission was led to find “that the relationship between physicians and patients is dynamic, that disclosures are extensive, that understanding and satisfaction are high, that decisionmaking is shared . . . .” Putting it this way is too disturbingly reassuring.

The Commission’s aspirations “to foster a relationship between patients and professionals characterized by mutual participation and . . . by shared decisionmaking” find little historical precedent or contemporary support in the ethics and practices of the medical profession, and it barely emerges in the common law doctrine of informed consent. Such a view is, at best, only that of a small band of commentators.

To be sure, Anglo-American law and our democratic society have for centuries espoused a commitment to individual autonomy. However, the question of whether citizens’ autonomy shall, or can, be honored once citizens become patients has not been decisively answered in the affirmative. Indeed, in medical and legal practice that question has been treated largely with angry or ironic disdain.

11 Id. at 401.
12 1 President’s Commission, supra note 1, at 10.
13 Id. at 36.
14 See supra note 3.
16 [U]nder a free government at least, the free citizen’s first and greatest right, which underlies all the others—the right to the inviolability of his person, in other words, his right to himself—is the subject of universal acquiescence, and this right necessarily forbids a physician or surgeon, however skillful or eminent . . . to violate without permission the bodily integrity of his patient . . . and [to operate] on him without his consent or knowledge.

Pratt v. Davis, 118 Ill. App. 161, 166 (1905), aff’d, 224 Ill. 300, 79 N.E. 562 (1906); see also Canterbury v. Spence, 464 F.2d 772, 780 (D.C. Cir.) (“[t]he root premise is the concept, fundamental in American jurisprudence, that ‘[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body’”) (quoting Shloendorff v. Society of New York Hosp., 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914)), cert. denied, 409 U.S. 1064 (1972); Natanson v. Kline, 186 Kan. 393, 406–07, 350 P.2d 1093, 1104 (1960) (“Anglo-American law starts with the premise of thorough-going self determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment.”).

17 For instance, recent statements by physicians show an antipathy toward patient auton-
I. THE REPORT AS A CONSENSUS DOCUMENT


The strong pull for a consensus document casts a shadow over this Report as it has over innumerable others. I do not wish to dismiss the need for accommodation among members of any commission so that a reasonable joint report can emerge. Instead, I wish to suggest that in situations where a commission proposes a fundamental reorientation in ethical practices—in this instance in a profession's practices that affect the well-being of society in decisive ways—any attempt at writing only a consensus document invites the danger of obscuring the problems of, and the obstacles to, implementation. The Commission's Report begs for the inclusion of majority and minority views. Morality, I believe, requires the presentation of disparate views, if only to bring to policymakers' and the public's attention the complexities of finding solutions to such tragic moral problems as the ones addressed by this Commission.

My personal views on the morality of individual dissent are not shared by others who also deserve a respectful hearing. Morris Abram, the Chairman of the President's Commission, and Susan Wolf, in reflecting on the work of the Commission, recently argued that "consensus among commission members [is] essential":

A commission such as this one has only the power of persuasion. A group performing ethical analysis, with no coercive powers, cannot be persuasive without internal agreement. Unlike a court or legislature, which is structured to have effect as long as a majority agrees, a commission requires agreement that is as close to unanimity as possible, to have any effect at all. Without such virtual unanimity, the commission members simply voice the possible arguments; with it, the commission can persuade.\footnote{Abram & Wolf, Public Involvement in Medical Ethics: A Model for Government Action, 310 New Eng. J. Med. 627, 629 (1984).}

My differences with the Commission's Chairman deserve careful

\footnotetext{\textit{om}y. See, e.g., Coleman, Terrified Consent, 2 Physician's World 5, 5 (1974) ("[t]here oughta be a law against this law"); DeLee, Malpractice and Informed Consent—A Legal Ploy: The Meaning of Informed Consent and Why it is a Deterrent to Sound Medicine, 61 Int'l Surgery 331, 332 (1976) (informed consent endangers patients' mental and physical life); Laforet, The Fiction of Informed Consent, 235 J. A.M.A. 1579, 1584 (1976) (informed consent "destroys good patient care"); Ravitch, The Myth of Informed Consent, 1 Surgical Rounds 7, 8 (1978) (informed consent can "fill patients with uncertainties or torture them with potentialities however remote").}
study. They have far-reaching implications about the functions that commissions such as this one are to serve. Our differences powerfully affect both the content of any final report and, by what is omitted and compromised, its ultimate value to policymakers, be they legislators or educators.

In the process of preparing the various drafts of the Report, the tensions among the Commission staff and between the staff and the Commissioners must have been formidable.\(^{19}\) Arriving at an acceptable consensus document must have been laden with agonizing choices, which discretion precluded airing. The morality of commission reports, past and future, requires study of the question whether societal morality is better served by documenting the complexities inherent in any ethical recommendation for the conduct of human affairs than by making light of the complexities through striving for a consensus report.

II. OBSTACLES TO SHARED DECISIONMAKING

Powerful resistance and formidable obstacles oppose the Commission’s objective of “shared decisionmaking” and deserve to be addressed with greater candor: (1) the absence of a medical tradition for patient participation in decisionmaking;\(^{20}\) (2) the lack of a coherent legal doctrine of informed consent, particularly one that is based on a thoroughgoing commitment to individual self-determination;\(^{21}\) (3) the pervasiveness of medical uncertainty;\(^{22}\) and (4) the incapacity of physicians in today’s world to engage patients in a shared decisionmaking dialogue.\(^{23}\)

A. The Absence of Medical Tradition for Patient Participation in Decisionmaking

Disclosure and consent, except in the most rudimentary fashion, are obligations alien to medical thinking and practice. Disclosure in medicine has served the function of getting patients to “consent” to what physicians want patients to agree to in the first place. Shared decisionmaking has no tradition in the ethics of medical practice.\(^{24}\)

\(^{19}\) See Bayer, Ethics, Politics, and Access to Health Care: A Critical Analysis of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 6 Cardozo L. Rev. 303 (1984).

\(^{20}\) See J. Katz, supra note 3, at 1–29.

\(^{21}\) See id. at 48–84.

\(^{22}\) See id. at 165–206.

\(^{23}\) See id. at 130–64.

\(^{24}\) Hippocrates, the revered father of western medicine, admonished physicians to:

[perform [their duties] calmly and adroitly, concealing most things from the pa-
The odd status of the concept of autonomy in medical thought makes this abundantly clear: Physicians have always insisted that they be granted autonomy; the idea of patient autonomy, on the other hand, is not found in the vocabulary of medicine.

In the political arena, in consulting rooms, and in hospitals, physicians have vigorously championed their prerogative for autonomous conduct under the slogan of “freedom from lay control.”

One does not need to go back to Hippocrates to document this truth. Morris Abram has provided us with a vivid and poignant depiction of his own struggles against the systematic disregard of patient autonomy that filters down from physicians to the rest of the medical personnel—a disregard that occasionally can be overcome if one has the will to scream loud enough:

I kept fighting through all the fevers and transfusions. I felt I could only survive it by insisting on control. And there would be plenty of chances to test my resolve. The personnel assigned to monitor various functions never coordinated their blood sample requirements on a given day, so they’d come two or three times to leech my tender, collapsing veins. I finally put my foot down.

“You’re not going to take more blood,” I shouted. “You take it once a day. Get together and find out how much you want and for what purpose, and, goddam it, in the absence of an emergency, don’t you touch my veins. Also, no one’s going to draw blood except the intravenous nurse team,” I said, “because that’s all they do, and they know how to do it.”

I got my way in both instances, thereby saving myself considerable pain. I was doing everything I could to avoid being an invalid, or a good patient.

By dint of strength of personality and legal eminence, Abram, unlike most patients, succeeded in avoiding being disregarded. He refused to succumb to being “a good patient”—that is, being a “good” child who is seen but not heard—or to being treated as an “invalid,” another metaphor for an obedient child.

According to medical tradition, however, good patients surrender their autonomy. Let me repeat, because only once we take notice does it strike us as odd: There is no concept of patient autonomy in medicine. As the Commission Report observed, “[m]edical skepti-

cism of patients’ capacities for self-determination can be traced to the
time of Hippocrates.”27

The Commission refers to records of daily medical practice that
reveal “distinct ‘indigenous medical traditions’ of truth telling and
consent-seeking, grounded on the theory that such knowledge ‘had
demonstrably beneficial effects on most patients’ health.’ ”28 This ob­
servation misinterprets history.

First, as Richard C. Cabot’s writings on truth telling clearly
demonstrate, truth telling only serves the purpose of reinforcing pa­
tients’ “trust” and physicians’ authority by establishing a more honest
relationship between physicians and patients.29 As I have written
elsewhere,30 the importance that Cabot, and for that matter Benjamin
Rush and John Gregory,

assigned to trust was based on [their] conviction[s] that good medi­
cal custody required it, and not that patient liberty dictated it. . . .

. . . Since trust between physicians and patients is a requisite
for joint decision making, [Cabot and others] addressed one of the
necessary preconditions for mutual deliberations. [They] did not
take a next step: to advocate that physicians and patients make
decisions jointly.31

Second, “consent-seeking” throughout medical history bears lit­
tle, if any, relationship to what the President’s Commission advocates
under the rubric of “shared decisionmaking.” Consent-seeking was
not based on ideas of equality, liberty, and/or autonomy. Instead, it
was grounded in the proposition, as Talcott Parsons put it, that “the
doctor-patient relationship has to be one involving an element of au­
thority—we often speak of ‘doctor’s orders.’ ”32 Consent-seeking
meant obedience to doctors’ orders, saying “yes,” or remaining silent,
and by such silence indicating acquiescence; but no more than that.

It is important to keep this history in mind. Otherwise, the enor­
mity of the task of implementing the noble aspirations of the Commis­

27 I President’s Commission, supra note 1, at 32.
28 Id. (quoting M. Pernick, The Patient’s Role in Medical Decisionmaking: A Social His­
tory of Informed Consent in Medical Therapy, reprinted in 3 President’s Commission, supra
note 1, at 1–35). But see J. Katz, supra note 3, at 15–16 (arguing that, historically, truth telling
was used as a means of manipulating the physician-patient relationship).
29 Cabot, The Use of Truth and Falsehood in Medicine: An Experimental Study, 5 Am.
Med. 344 (1903), reprinted in Ethics in Medicine: Historical Perspectives and Contemporary
Concerns 213 (1977).
31 Id. at 26.
sion's recommendations will remain unappreciated. When the Commission speaks of "informed consent . . . [as] essentially an ethical imperative," I agree wholeheartedly. It is, however, an ethical imperative that comes not from the ethos of medicine, but from elsewhere. The traditional ethical imperatives of medicine speak a different language.

Medicine's language and that of the Commission still must be reconciled. And, although it is not apparent from the Commission's Report, that reconciliation has to begin at square one. The Lidz and Meisel study makes this stark fact abundantly clear. The repeated reference to the Harris poll only obfuscates this reality; that survey deserves to be relegated to oblivion.

If I am correct, then the call for "[c]urricular innovations aimed at preparing health professionals for a process of mutual decision-making with patients" will prove to be more difficult to implement than appearances suggest. At best, only a handful of physician-teachers have begun this task. Most physician-teachers are not committed to the value of shared decisionmaking. Whatever courses and seminars exist on this topic are taught largely by nonphysicians. And as Derek Bok recently observed, such courses and seminars "carry a message that [they] are of slight importance in the total curriculum . . . , that none is important enough to be required of every doctor."

We must be grateful to the philosophers, bioethicists, lawyers, ministers, priests, and rabbis who have tried to alert future physicians to their decisionmaking responsibilities toward patients. But where have the physician-teachers been? They need to be recruited and trained.

Physician-teachers must become more involved in preparing medical students for the challenges of shared decisionmaking. Otherwise, students will not become sensitized through identification with their elders to their new responsibilities. To quote Bok once again,

33 1 President's Commission, supra note 1, at 2.
34 The ethical imperative comes from law, see supra note 16, and from philosophy, see, e.g., I. Kant, Groundwork of the Metaphysic of Morals (H. Paton trans. 1964).
35 See supra notes 9–11 and accompanying text.
36 Even though the President's Commission noted that "[r]egarding health care, surveys are known to overstate the frequency with which information is disclosed and may present a rosier, more homogeneous picture of medical practice than an on-site investigation," 1 President's Commission, supra note 1, at 9, the Report seems again and again to rely on the Harris poll in support of the proposition that the physician-patient relationship "is dynamic, that disclosures are extensive, that understanding and satisfaction are high." Id. at 10.
37 1 President's Commission, supra note 1, at 4.
“physicians will often command greater respect than priests or social workers in convincing patients [and medical students, I would add] of the steps they need to follow to cure . . . disease or avoid future illness.”

I have trained more colleagues from other disciplines than from medicine; law schools, more than medical schools, have been hospitable to the exploration of issues of professional responsibility. If medical faculties wish to reverse the historical disregard of patients’ decisionmaking capacities, they cannot complacently turn to the current guardians of decisionmaking education. Juvenal understood this well with respect to chastity:

During Saturn’s reign I believe that Chastity still
Lingered on earth . . . .
Thereafter, by slow degrees,
Justice withdrew to heaven, and Chastity went with her . . . .
To bounce your neighbour’s bed . . . . to outrage
Matrimonial sanctity is now an ancient and long-established tradition. . . .

I know the advice my old friends would give—‘Lock her up
And bar the doors.’ But who is to keep guard
Over the guards themselves?

B. The Lack of a Coherent Legal Doctrine of Informed Consent

The President’s Commission correctly observed that “[t]he realities of court decisions on informed consent . . . fall short of the law’s professed commitment to the value of self-determination.” The Commission went on to say:

Since “the courts imposed primarily a duty-to-warn on physicians,” thereby avoiding a judicial recognition of the proposition that patients have a decisive role to play in the medical decision-making process, they have merely reinforced “physicians’ traditional monologue of talking at and not with patients.” As a result

39 Id at 39. Bok went on to say:
In the ethos of the contemporary medical school, with its strong emphasis on biomedical science, subjects such as . . . patient psychology, ethics, and health care policy must be required and given ample time if we expect more than a small minority of students to study them seriously. Faculty members will complain that there is no room to force these courses into an overstuffed curriculum . . . . Yet space can and must be found, whether it comes from elective slots or from time freed up by pruning unnecessary detail from the basic science courses.

41 1 President’s Commission, supra note 1, at 29.
they have missed the opportunity to move toward what is needed: "a new and unaccustomed dialogue between physicians and their patients . . . in which both, appreciative of their respective inequalities, make a genuine effort to voice and clarify their uncertainties and then to arrive at a mutually satisfactory course of action."\(^\text{42}\)

In light of the Commission's and other commentators' observations, it is quite apparent that the call for "shared decisionmaking," a felicitous phrase adopted by the Commission, has only created an atmosphere in which shared decisionmaking has the potential to survive and grow. The doctrine has not yet provided a meaningful blueprint for implementing patient self-determination.

Nevertheless, the Report goes on to say that "[t]he Commission encourages, to perhaps a greater degree than is explicitly recognized by current law, the ability of patients and health care professionals to vary the style and extent of discussion from that mandated by this general presumption."\(^\text{43}\) There is no "perhaps" about the Commission's contention, for the Commission correctly asserts on the next page of its Report that "its description of mutual participation and shared decision making sets a high ideal."\(^\text{44}\) It is an ideal, however, to which the legal doctrine has paid only lip service.

It is understandable that the Commission did not wish to underscore its radical departure from the informed consent doctrine and chose to highlight instead the minimal requirements for shared decisionmaking embedded in the doctrine.\(^\text{45}\) Any forthright acknowledgments of this departure might have led physicians to appreciate that the supposedly onerous obligations of disclosure and consent imposed by common law judges are not as onerous as they have been perceived.

\(^{42}\) Id. at 29–30 (footnotes omitted).

\(^{43}\) Id. at 38 (emphasis added).

\(^{44}\) Id. at 39.

\(^{45}\) While the idea of informed consent emerged out of recognition that patients deserve a greater voice in medical decision-making, the single-minded emphasis on risk-disclosures and, to a lesser extent, on alternatives, made this objective unattainable. For mere disclosure does little to expand opportunities for meaningful consent, particularly in surrender-prone medical settings, unless patients are also seen as potential participants in medical decisions affecting their lives. This is not the view of physicians who instead see themselves as ultimate decision-makers. By limiting the ostensibly new disclosure duties to traditional medical practices, judges did little to shake this view.

Katz, supra note 15, at 172–73. For shared decisionmaking to be meaningful, as advocated by the President's Commission, courts must inquire not so much whether a particular disclosure has or has not been made, but rather whether "the nature and quality of the entire give-and-take process" between physician and patient was a joint undertaking and led to a meeting of two minds. Id. at 173 (emphasis added).
Physicians’ resistance to shared decisionmaking might have stiffened, and longstanding professional attitudes against disclosure and consent might have received support from a newly discovered friend—law—which for decades has been seen as an adversary instead.\(^{47}\)

It is equally understandable that the Commission wished to underscore the symbolic significance of its call for “shared decisionmaking” in order to nag, prod, and disturb the medical profession. Perhaps it felt that doing so would ultimately improve the climate of physician-patient decisionmaking.

Whatever the reasons, the Commission adopted a strategy of obscuring the differences between the legal doctrine of informed consent and its objective of “shared decisionmaking.”\(^{48}\) I wish the Commission had made it clearer that its Report addresses not, as its subtitle suggests, “the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship,” but rather the ethical implications of shared decisionmaking in the patient-practitioner relationship.

Distinguishing between the legal doctrine of informed consent and “shared decisionmaking” would have alerted physicians that the legal doctrine is a confusing patchwork of contradictory themes.\(^{49}\)

\(^{46}\) The total absurdity of the [doctrine of] . . . informed consent is a self-contradictory absurdity mitigated only by the obvious piety of the wish that the patients . . . might fully understand what is being proposed. . . . However, there is no way that I can see that a parent can arrive at a proper judgment as to whether an infant with Hirschsprung’s disease is to be treated by the Swenson, the Duhamel or the Soave operation . . . .

\(^{47}\) See supra note 17.

\(^{48}\) Compare 1 President’s Commission, supra note 1, at 29 (“[t]he realities of court decisions on informed consent thus fall short of the law’s professed commitment to the value of self-determination”), and id. at 30 (“[c]urrent law serves the important purpose of encouraging health care professionals to disclose important facts to patients . . . . The law also serves a critical moral and educative role in proclaiming (even if not always fully enforcing) the value of self-determination.”). Insufficiently emphasized and explicated, although hinted at, are law’s minimal requirements for informed consent. In not giving them the deserved emphasis, the confused state of the informed consent doctrine was not brought clearly to physicians’ attention. See infra note 49.

\(^{49}\) For example, in Natanson v. Kline, 186 Kan. 393, 409-10, 350 P.2d 1093, 1106 (1960), the court established a disclosure standard based on the practices of a “reasonable medical practitioner,” while in Canterbury v. Spence, 464 F.2d 772 (D.C. Cir.), cert. denied, 409 U.S. 1064 (1972), the court declared “[r]espect for the patient’s right of self-determination on [a] particular therapy demands a standard set by law for a physician rather than one which physicians may or may not impose on themselves.” Id. at 784 (footnotes omitted). There is a similar confusion with regard to establishing the necessary causal connection between a physician’s failure to adequately inform the patient and the patient’s decision whether or not to
The Commission then could have observed not merely that the informed consent doctrine "is only dimly perceived . . . and perhaps even misunderstood" by physicians, but also that doctors have good reasons to dimly perceive and misunderstand it. I have been a student of the doctrine for years, and I do not understand it, if understanding means more than merely identifying its confusing and contradictory pronouncements and prescriptions.

On the other hand, "shared decisionmaking," the Commission's prescription, is a much more coherent statement of the scope of physician-patient decisionmaking. It builds on the idea of patient self-determination that underlies informed consent—an idea that judges quickly lost sight of as they translated the idea of self-determination into their doctrine of informed consent. It is important to appreciate fully that the Commission advocates not only a radical break with longstanding medical practices, but with case law as well. I applaud the Commission's move. The beleaguered status of shared decision-making, however, deserves emphasis so that the new vision championed by a small band of commentators, and now by the President's Commission, can emerge more clearly and be subjected to scrutiny.

C. The Pervasiveness of Uncertainty

I have written elsewhere about the pervasiveness of medical uncertainty and suggested that, in this age of medical science, uncertainty of knowledge is no longer as significant an obstacle, either to shared decisionmaking or to disclosure and consent, as is the reluctance and inexperience of physicians in coping better with uncertainty. Moreover, the problem is not the difficulty of communicating uncertainty to patients, but rather physicians' lack of

forego treatment. The Canterbury court opined that the question for the jury is not what the patient would have decided to do had the physician adequately informed him, but "what a prudent person in the patient's position would have decided if suitably informed." Id. at 791. On the other hand, the court in Scott v. Bradford, 606 P.2d 554 (Okla. 1979), stated that the Canterbury court's " 'reasonable man' approach . . . severely limits the protection granted an injured patient. . . . If [the patient] testifies he would not [have agreed to the proposed treatment], then the causation problem must be resolved by examining the credibility of [his] testimony." Id. at 559 (emphasis added).

50 1 President's Commission, supra note 1, at 17 (emphasis added).
51 For example, in Natanson v. Kline, 186 Kan. 393, 350 P.2d 1093 (1960), the court, while basing the informed consent doctrine on Anglo-American law's "premise of thorough-going self-determination," id. at 406, 350 P.2d at 1104, immediately limited disclosures to the practices of "a reasonable and prudent medical doctor of the same school of practice as the defendant under similar circumstances." Id. at 411, 350 P.2d at 1107. Thus, when the court's impulse to foster individual self-determination collided with the equally strong desire to maintain the authority of the professions, the former was given all too short shrift.
52 J. Katz, supra note 3, at 165-206.
training for uncertainty. The problem is for doctors to confront more honestly diagnostic and therapeutic uncertainties and, in turn, acknowledge them to patients as an integral aspect of their treatment recommendations.

The physicians' disregard of uncertainty, not in theory but in interaction with patients, is telling proof that doctors have been trained and socialized not for coping with uncertainty, but for substituting certainty instead. The posture of certainty is reinforced by the traditional authoritarian interaction—inimical to shared decisionmaking—that pervades physician-patient relations and that doctors seek to foster. Professing certainty serves to maintain professional power and control over the medical decisionmaking process. Physicians' power and control is maintained not only by projecting a greater sense of certainty than is warranted, but also by leaving patients in a state of uncertainty, not in the sense of shared uncertainties but in the sense of keeping patients in the dark.

The disregard of uncertainty defeats sharing the burdens of decision with patients. Such disregard has significantly contributed to the duplicities, evasions, and lies that readily permeate conversations

53 Id. at 184–86. But see Fox, Training for Uncertainty, in The Student-Physician 207 (1957) ("as time goes on, a student begins to develop effective ways of dealing with . . . forms of uncertainty, so that, gradually, he becomes more capable of meeting them with the competence and equipoise of a mature physician").


55 In Haley v. United States, 739 F.2d 1502 (10th Cir. 1984), a court, for the first time, addressed the obligation of physicians to disclose uncertainty:

[N]either [physician] adequately disclosed his uncertainty about whether [the patient] had Crohn's disease or ulcerative colitis. Dr. Jay Katz, the leading authority on the doctrine of informed consent, has written:

"All professions possess esoteric knowledge that, in its totality, is difficult to learn, understand, and master. Indeed, the complexity of professional knowledge commands the laity to listen carefully to experts. It does not necessarily suggest, however, that this knowledge cannot be communicated to, or understood by, patients. Nor does it suggest that professionals should decide how to proceed without consulting patients, particularly if alternatives are available and treatment is beset by much uncertainty. These considerations become even more relevant if it is also correct, as I believe it is, that physicians have during this century acquired a greater capacity than they had heretofore to make distinctions between what they know, do not know, and what is as yet unknowable; that they have acquired the capacity, paradoxical as it may sound, to talk more knowledgeably about their ignorance."

J. Katz, The Silent World of Doctor and Patient 92 (1984). For [the patient] to appreciate the risks associated with rectal surgery she had to be apprised that the doctors were only speculating about the possibility of cancer.
with patients. Such disregard makes meaningful disclosure and consent a charade.

Unless physicians learn to deal better with uncertainty, unless future physicians become better trained for uncertainty, shared decisionmaking will not become a meaningful reality. Training for uncertainty is one of the most pressing assignments confronting medical educators, an assignment for which no committed and respected place has been found in the curriculum.

D. The Incapacity of Physicians to Engage Patients in a Shared Decisionmaking Dialogue

My all too brief discussion of uncertainty has alluded to the fact that coping with uncertainty may be more a problem for physicians than for patients. If I am correct, doctors' disregard of uncertainty—and not patients' incapacity to understand—constitutes the initial barrier to shared decisionmaking. Indeed, it is not at all clear how much patients' alleged incapacities are a consequence of physicians' lack of training for communicating uncertainty to their patients.

Shared decisionmaking will not become a reality until physicians disabuse themselves of their collective fantasy that they do initiate discussions about uncertainty of diagnosis and that they do initiate discussion about uncertainty as to what constitutes the best treatment. Change will only come about if doctors confront, and then alter, the current reality—so well depicted in the Lidz and Meisel study—that "[e]ven when there is a high degree of uncertainty about a patient's problem, . . . [the] medical personnel trie[s] to convey a sense of certainty rather than subtle information about the illness and its treatment." How to supply information about uncertainty requires a massive effort at reeducating physicians and giving patients a greater appreciation of the uncertainties that haunt the practice of scientific medicine.

Before physicians can acquire the capacity to share the burdens of decision with patients, many problems will require exploration. I have selected two that are closely related to uncertainty: the tension between intervention and delay, and the management of patients' transferences.

56 See J. Katz, supra note 3, at 142-54, 189-99.
57 The Harris poll suggested that 90% of physicians believe they initiate discussion about uncertainty of diagnosis and 66% believe they initiate discussion about uncertainty of treatment. 1 President's Commission, supra note 1, at 87.
58 Lidz & Meisel, supra note 9, at 317-410.
59 1 President's Commission, supra note 1, at 89.
1. Intervention or Delay

Physicians' pervasive failure to acknowledge uncertainty to pa­
tients is influenced by medicine's considerable ignorance of the respec­
tive contributions that *vis medicatrix naturae*—the healing power of
nature—and physician's interventions make to the healing process.
These uncertainties in medical knowledge raise a most vexing ques­
tion: When is nonintervention just as salutary as intervention?

Traditionally, doctors have resolved this question by resorting to
action on the assumption that doing something is better than doing
nothing and that errors of commission are less reprehensible than er­
rors of omission. Acting on such assumptions in the face of uncer­
tainty relieves the tension of living with the possible, yet unknown,
harmful consequences of delay, since harm caused by mistakes of in­
tervention can more readily be ascribed to the natural progression of
the underlying disease process. Thus, particularly in the absense of
any acknowledgment of uncertainty, errors of omission can more eas­
ily be blamed on physicians than can errors of commission. Acknowl­
edgment of uncertainty about intervention or delay to patients, on the
other hand, would compel both doctors and patients to share respon­
sibility for the decision ultimately made.

Physicians have justified their proclivity to intervene on the
ground that patients demand action rather than watchful waiting.
Doctors have overlooked, however, their contributions to the creation
of such "demands" by their own deep-seated preference for resolving
any ambiguity about treatment in favor of intervention. Fostering
such expectations in patients has made acknowledgment of uncer­
tainty about action or delay unnecessary since both parties seem to
share the same preference.

Yet, the preference for treatment over watchful waiting has
many consequences. For example, it can make "patients" out of per­
sons who, with proper education, could rely more on their own self­
healing capacities. It also exposes these "patients" unnecessar­ily to
the iatrogenic complications of the powerful treatments of modern
medical technology, when either no treatment or a less drastic ther­
apy is a viable alternative.

The high rate of "unnecessary" surgery and of resort to antibiot­
ics and tranquilizers bears testimony to physicians' propensity to resolve uncertainty and ambiguity through action rather than inaction. To turn the tide would require a massive reeducation of physicians and patients. Both must learn that there is considerable value in living with uncertainty and not resolving it preemptorily in favor of intervention. Delay imposes its own risks to life and health and also imposes considerable economic costs to individuals and society; but so does action, and perhaps to an even greater extent. Lest I be misunderstood, let me note that I favor neither intervention nor delay, but only the proposition that both are meaningful alternatives and that ultimately a patient must make the choice as to which route to follow.

2. Transference

Shared decisionmaking requires an appreciation of one particular set of irrational feelings—transference—that patients bring to their encounter with doctors. The term transference encompasses the patients' proclivity to endow their doctors with the characteristics of patients' earliest caretakers rather than to appraise the capabilities of physicians more realistically. The process of transference leads patients to project onto the doctor all kinds of magical expectations, hopes, and fears that are intrinsically irrational because they emerge out of the confusion of past with present and of fantasy with reality.

These irrationalities manifest themselves most dramatically in the overvaluation of the physician as an omnipotent healer. The ubiquitous emergence of such feelings in all physician-patient interactions bears testimony to the existence of psychological vulnerabilities inherent in human beings that only become magnified in the presence of uncertainty over health and cure. Patients' basic modes of expression of such feelings are in many ways predictable and stereotypical, but transference's subtler manifestations also reveal facets of an individual's uniqueness and essence, of his or her personality, as it has evolved in interactions with parents and other important persons during childhood years. Thus, manifestations of transference constitute a mixture of highly individualized personal reactions as well as universal human adult and childlike longings that possess both rational and irrational components. Transferences can guide and misguide per-

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63 See J. Katz, supra note 3, at 142–47.
sons; the latter mostly in times of stress, when infantile hopes and fears surface most insistently.

If physicians were to acquire a greater appreciation of these proclivities, it would prevent their being seduced by their patients’ apparent initial willingness to submit unconditionally to their “parent-doctors.” Instead, doctors might take greater care to avoid disappointments, engendered by magical hopes, by challenging patients’ unquestioning readiness to put themselves in their doctors’ hands. If physicians were to recognize that patients’ magical expectations must be moderated by confronting patients with medical realities, then physicians might more carefully combine expressions of hope with a more realistic appraisal of patients’ medical conditions.

Physicians also need to appreciate that they are not only the victims of these transferences, but their abettors as well. Because they have been as blind to the existence of transference as have their patients, doctors have encouraged and augmented patients’ transference feelings by unwittingly promising more than they can deliver, or by not confronting their patients’ explicit and implicit unrealistic expectations. An essential precondition for more effective communication is a greater awareness by both parties of the power of transference and the obligation to contain its power. Initially, this obligation must be assumed by professionals rather than by their patients. Patients can learn of the power of transference only over time and through personal experiences with aware physicians who educate them about its manifestations.

Awareness could lessen physicians’ temptation to contribute to the regressive pull either actively, by treating patients as children, or passively, by keeping patients in the dark and not inviting their participation in decisionmaking. Indeed, patients’ transference reactions have reinforced physicians’ traditional view of patients’ incompetence. Under the domination of transference, patients appear more childlike than they actually are or necessarily need to be. Physicians have been blinded by these ubiquitous and spontaneous manifestations of transference and have not fully appreciated that patients are not children.

If doctors were more aware of transference, they would more readily discern that, manifestations of childlike behavior notwithstanding, the patient is a mature adult. Doctors would then be more inclined to learn how to address and nurture the intact, mature elements of a patient’s functioning and how to reverse the regressive pull engendered by illness and its attendant anxieties. Anna Freud tried to
teach these lessons of transference to students at Case Western Reserve Medical School by reminding them that:

The patient . . . will do his best to push you into the place of parental authority, and he will make use of you as parental authority to the utmost. You must understand that. On the other hand, you must not be tempted to treat him as a child. You must be tolerant towards him as you would be towards a child and as respectful as you would be towards a fellow adult, because he has only gone back to childhood so far as he's ill. He also has another part of his personality which has remained intact, and that part of him will resent it deeply, if you make too much of your authority.64

Misled by the phenomenon of transference, physicians have thought that patients had wanted them to assume complete authority and, therefore, have issued orders. When their orders made patients even more childlike—submissive or obstreperous—doctors did not separate the contributions that the disease, the physician, and the patient made to the regression. Traditional patterns of interaction between physician and patient have made childlikeness a self-fulfilling prophecy.

Reconciling respect for self-determination with respect for patients' adult and childlike longings is a difficult undertaking. How to achieve such a reconciliation through shared decisionmaking requires intensive study, and then, in fidelity to the Hippocratic Oath, a commitment to "[imparting] a knowledge of the Art to [our] own sons"65 (and daughters, I would add).

III. WELL-BEING AND SELF-DETERMINATION

Before concluding, let me comment on the Commission's assertion that informed consent is based on two values: well-being and self-determination.66 While reading the earlier chapters of the Report, I was uncertain whether the Commission limited "well-being" to health related issues or also included under its rubric the well-being that can accrue to persons from being active participants in decisions that affect their lives in such decisive ways. If employed in the latter sense, the inclusion of well-being as an aspect of self-determination would seem justified, although it would have introduced new complications. But later on, the Report made it clear that well-being is only meant in

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66 1 President's Commission, supra note 1, at 41.
the former sense: "[T]he absence of self-determination [does not interfere] with the promotion of the patient's well-being." Why informed consent—the obligation to disclose information and seek patients' consent—should be based on the value of physical well-being, the Commission did not discuss at length.

The conjunction of well-being and self-determination as values underlying informed consent is unfortunate. It led the Commission to recommend that "possibly competing considerations of well-being and self-determination [must be balanced, and that] the prudent course is to take into account the potential consequences of the patient's decision." Since it is the physician's task to take well-being into account, the Commission returns us to the days before the case of *Canterbury v. Spence* by resurrecting under the balancing test the medical standard of care and the therapeutic privilege with respect to decisionmaking.

Yet, the Commission also realized both that "no objective medical criteria [exist] that specify a single best way to achieve the goal [of promoting health]" and that "[w]hich treatment is better can be unclear, even to a physician." Giving well-being equal status with self-determination—in the absence of any objective criteria of what constitutes health, in the presence of pervasive medical uncertainty, and in a climate of medical authoritarianism—can only reinforce physicians' proclivities to remain stuck in the mire of making decisions, not by sharing the burdens of decisions with patients, but by invoking "the best interest" test, now called the "well-being" test.

I share the Commission's concern about patients' well-being, but the Commission went too far in its defense by asserting, for example, that "the well-being principle circumscribes the range of alternatives offered to patients: informed consent does not mean that patients can insist upon anything they might want." Although patients should not, of course, be able to insist upon any treatment they choose, their wishes ought to be heard, not stifled by circumscribing the range of alternatives offered them. In today's medical world it is too dangerous a recommendation.

Equally problematic is another suggestion that emerges from the

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67 Id. at 45.
68 Id. at 60.
70 See supra note 49.
71 1 President's Commission, supra note 1, at 42.
72 Id. at 43.
73 Id.
Commission's discussion of "standards for assessing [decisionmaking] capacity":

When little turns on the decision, the level of decisionmaking capacity required may be appropriately reduced (even though the constituent elements remain the same) and less scrutiny may be required about whether the patient possesses even the reduced level of capacity. Thus a particular patient may be capable of deciding about a relatively inconsequential medication, but not about the amputation of a gangrenous limb.\footnote{Id. at 60.}

Such a prescription can be read, however much unintended by the Commission, as allowing patients to make "inconsequential" but not important decisions. Concern over "well-being" can readily obliterate concern for self-determination. In light of the Commission's ideal of "shared decisionmaking," I believe that it did not wish to be so misread. Yet it will be.

Well-being is modified by the Commission in two ways: "personal well-being" and "patient well-being." I have already alluded to the change in physicians' perception of, and attitudes toward, persons once they are labelled patients. If they were viewed as autonomous before, they no longer are. Thus, physicians' concern over patient well-being tends to obliterate concern over personal self-determination.

Perhaps at some time in the future, when patient autonomy has found a respected place in the ethos of medicine, well-being and self-determination can be juxtaposed as the two values underlying informed consent. That day, however, is far away, at best. Physicians will first have to become more sensitive to how their own perceptions of themselves and their patients affect their respective commitment to the values of self-determination and well-being. One lay commentator's observations, generally shared by doctors, illustrate the problem:

Recently, I wrote out what I espouse as the standard governing informed consent between doctor and patient, and the philosophy that lies behind it. In fact, I believe that the skillful doctor, metaphorically speaking, throws out a rope to the patient drowning in illness and by encouraging the patient to hold on furthers the healing process.\footnote{M. Abram, supra note 26, at 116.}

With respect to "well-being," the metaphor may be apt. With respect to self-determination, however, both physician and patient often begin at sea, and only after having engaged in the process of shared decisionmaking may both regain common and firm ground. Any mean-
ingful "standard governing informed consent" must clearly distinguish between these two disparate issues.

I suggest that shared decisionmaking be based only on the value of self-determination. The Canterbury court moved in that direction by stating that the doctrine must be grounded in "[t]he root premise . . ., fundamental in American jurisprudence, that 'e'very human being of adult years and sound mind has a right to determine what shall be done with his own body.'" That the court then departed from its root premise is another matter. Indeed, its departure was probably motivated in part by concerns similar to those of the Commission about protecting patients' well-being when their choices seem contrary to their perceived medical interest. Under these circumstances the Canterbury court believed that autonomy and self-determination should yield to well-being.

Autonomy, as I have written elsewhere, is a complex concept. It incorporates human beings' simultaneous proclivities for conscious and unconscious, rational and irrational thought and action. Thus, assuring physicians' and patients' optimal exercise of conscious and rational autonomous conduct requires the searching dialogue that the idea of "shared decisionmaking" seeks to foster.

Respect for psychological autonomy requires that both parties pay caring attention to their capacities and incapacities for self-determination by supporting and enhancing their real, though precarious, endowment for reflective thought. In conversation with one another, patients may uncover mistaken notions about their diseases and their treatment that they have held for a long time or have recently acquired through misunderstanding the import of their doctors' recommendations. Physicians may uncover the fact that their unconscious preferences and biases compelled patients to yield to their recommendations even though consciously they had intended otherwise. Without conversation, individual self-determination can become compromised by condemning physicians and patients to the isolation of solitary decision making, which can only contribute to abandoning patients prematurely to an ill-considered fate.

At the same time, patients' ultimate choices deserve to be honored except under the rarest of circumstances. The psychological dynamics underlying shared decisionmaking require the utmost

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76 Canterbury, 464 F.2d at 780 (quoting Schloendorff v. Soc'y of New York Hosp., 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914)).
77 J. Katz, supra note 3, at 104–29.
78 Id. at 128.
79 For a discussion of when patients' choices should not be honored, see id. at 156–63.
respect for patient autonomy with regard to choice; otherwise, the value of well-being all too readily compromises the value of self-determination.

It is far better to assign the value of well-being a subordinate place in the informed consent or, better yet, shared decisionmaking process. The Commission, I believe, struggled with this proposition and came close to adopting a similar view:

Given ... the frequent absence of objective medical criteria and the legitimate subjective preferences of patients, — ascertaining whether a health care intervention will, if successful, promote a patient’s well-being is a matter of individual judgment. Societies that respect personal freedom usually reach such decisions by leaving the judgment to the person involved.80

The Commission might have based shared decisionmaking solely on the value of self-determination if it had been as concerned as I am with the following problems. First, physicians are as vulnerable to the impact of unconscious and irrational influences on their recommendations as patients are vulnerable to the impact of these influences on their choices. The absence of “objective medical criteria” as to what constitutes well-being only aggravates this problem. Second, the interests of physicians and patients do not necessarily coincide. Their objectives can differ, particularly as long as alternative medical treatments, including no treatment, pose risks and confer benefits—whether physical, emotional, economic, or spiritual. Third, the lack of any medical tradition of shared decision making, coupled with the conviction that doctors are the appropriate guarantors of patients’ well-being, requires the sharpest possible separation between the values of self-determination and well-being; otherwise, the latter will all too readily swallow the former.

I attempted to deal with these issues in The Silent World of Doctor and Patient81 out of regard for shared decision making, a concern similar to that of the Commission. There I introduced distinctions between thinking about choices and choice, and I suggested that physicians and patients are obligated to participate in the process of thinking about choices but that choices are largely for patients to make and must be honored.82 Thinking about choices should be conducted in the spirit of better understanding physicians’ and patients’ expectations and differences, and not in the spirit of assessing competence, particularly as long as that assessment remains a unilateral and

80 1 President’s Commission, supra note 1, at 43.
81 J. Katz, supra note 3, at 85–164.
82 Id. at 105–29.
not a bilateral exploration of the physician's and the patient's competence. The entire notion of competence assessment ought to be discarded and replaced by the ideas of mutual exploration of difference in expectations, mistaken notions of misunderstandings, and much more.

To be sure, safeguarding the value of well-being will occasionally require overruling patients' choices. No principle can rule absolutely, including the principle of freedom of choice. Yet, exceptions must be narrowly circumscribed and justified. Such fateful decisions must be made with clear recognition, not that two values are being balanced, but that one is undermined out of respect for another. What I propose is not of small moment, for it moves respect for autonomy to center stage; it celebrates "shared decisionmaking" without allowing it to become compromised ab initio.

CONCLUSION

In concluding, I want to return to the beginning of this Article. I applaud and admire the Commission's bold and noble vision. The concerns I have expressed only seek to draw attention to the formidable obstacles that stand in the way of implementation. These obstacles must be addressed bluntly, slowly, carefully, unflinchingly, and in depth; for otherwise the vision will remain a mirage.

To accomplish all of that requires a committed effort that will take time. I urge those who will continue the Commission's work to proceed slowly. The unsatisfactory state of physician-patient decisionmaking has been with us for too long; it cannot be changed overnight. Recall the closing lines of an ancient poem by Al-Hariri:

Was man nicht erfliegen kann, muss man erhinken.
. . . Die Schrift sagt, es ist keine Sunde zu hinken
(What we cannot reach flying, we must reach limping.
. . . The books tell us it is no sin to limp).84

83 Id. at 104–29.
84 A free translation of one of the Maqāmāt of Al-Hariri in Die beiden Gulden, 6 Friedrich Rückert Werke 21 (C. Beyer trans. 1897).