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INFORMED CONSENT — MUST IT REMAIN A FAIRY TALE?*

Jay Katz, M.D.**

When the editors of the Journal of Contemporary Health Law and Policy asked me to contribute an article to their issue in honor of my friend, colleague and dean, Guido Calabresi, I accepted their invitation with pleasure. Since I had reflected about informed consent for two decades, I welcomed this opportunity to set forth my final thoughts and conclusions, however briefly and summarily, on this doctrine and its impact on physician-patient decisionmaking. This essay gives a good account of what I shall ever be able to say about informed consent.

It is appropriate that I choose this topic for this occasion because Guido has had a long standing interest in law and medicine. Twenty-five years ago, he published his remarkable paper, Reflections on Medical Experimentation in Humans,¹ and since then he has periodically written on issues in law and medicine. He has not, however, ever explored in depth the problematics of the legal doctrine of informed consent and, to the extent he has, only in the contexts of human experimentation and organ transplantation. If this essay will stimulate this great torts law scholar and teacher to give us his analysis and insights, we can only benefit from his wisdom.

In his article on human experimentation, Guido was mainly concerned with one crucial tension inherent in medical research: “our fundamental

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I wish to thank Sherwin Nulan and my research assistants Steven D. Lavine and Katherine Weinstein for their thoughtful contributions to earlier drafts of this essay. My wife, Marilyn A. Katz, as always, has commented on the many drafts and I am grateful for her critical wisdom which is reflected throughout this essay.

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¹ Guido Calabresi, Reflections on Medical Experimentation in Humans, 98 Daedalus 387 (1969).
need constantly to reaffirm our belief in the sanctity of life and our practical placing of some values (including future lives) above an individual life."\textsuperscript{2} He admonished scholars to "devot[e] themselves to the development of a workable but not too obvious control system, rather than to the spinning-out of theories of consent,"\textsuperscript{3} because "[t]otally free consent is simply too rare an animal."\textsuperscript{4} While I assign greater significance to consent as a mechanism of control than Guido does, I agree with him that "consent by itself is not enough."\textsuperscript{5}

Informed consent is a hybrid concept which speaks both to physicians' disclosure obligations and patients' willingness to undergo a particular treatment. Throughout this essay I intend to give prominence to the disclosure aspect of informed consent and its implications for improving the quality of patient consent. I would go further than Guido did, when he wrote that "\textit{some form of consent should always be required},"\textsuperscript{6} because I have greater faith in the crucial role that consent can play in doctor-patient decisionmaking once physicians learn to differentiate, which they have not, between acquiescence and consent. I shall have more to say about all this as I go along. In his recent, intriguing article, \textit{Do We Own Our Bodies?}, while addressing problems of organ transplantation, Guido comes close to issues that I shall explore in this essay:

\begin{quote}
I admit I am still an individualistic Kantian libertarian... I find it very hard to conceive of a situation in which the state should properly say: "Guido, you must give up that magnificent hair, blood, or marrow, to someone else regardless of your will... We owe it to ourselves... to do more thinking about something which seems, at first glance, outlandish — like the question: Do we own our own bodies?"\textsuperscript{7}
\end{quote}

Guido raised his "outlandish" question with respect to state-mandated interventions. How might he answer the question, "Do we own our own bodies?" in the context of the physician-patient relationship? I shall argue that physicians take too much license with patients' bodies and that the common law doctrine of informed consent has insufficiently addressed the question of who owns our bodies. In a different vein, Guido speaks to this question in \textit{Ideals, Beliefs, Attitudes, and the Law}:

\begin{thebibliography}{9}
\bibitem{2} Id. at 405.
\bibitem{3} Id.
\bibitem{4} Id. at 391.
\bibitem{5} Id. at 404.
\bibitem{6} Id. (emphasis added).
\bibitem{7} Guido Calabresi, \textit{Do We Own Our Bodies?}, \textit{1 Health Matrix} 17-18 (1991).
\end{thebibliography}
Have the lives we have prolonged been, in some sense, fruitful and rewarding (even if terribly handicapped)? Have we adhered to those beliefs, ideals and attitudes (including the ideal of letting people hold to their own kooky ideals) which may be dearer to us than an extra month on a life expectancy table? 

Physicians, as I shall argue later, have always placed greater value on longevity than on quality of life. To resolve these and other value conflicts alone requires searching conversation between physicians and patients. Without such conversation, informed consent will remain a hollow aspiration and preclude patients from exercising greater control over decisions which, in the end, only they can make.

Like Guido, though perhaps with modification, I too am “an individualistic Kantian libertarian,” and thus I give greater weight to autonomy and self-determination than perhaps he does. As I observed years ago:

Physicians have always maintained that patients are only in need of caring custody. . . . The idea that patients may also be entitled to liberty, to sharing the burdens of decision with the doctors, was never [at least until recently] part of the ethos of medicine. Being unaware of the idea of patient liberty, physicians did not address the possible conflict between notions of custody and liberty.

In this essay I shall also argue that formidable problems exist which require study and resolution before informed consent can ever safeguard patient autonomy and self-determination. The likely outcome of such inquiries will be to return ownership of bodies to patients and to not allow caring custody to mislead physicians and patients into believing that ownership must temporarily be transferred to doctors’ “discretion.” Law has an important role to play here by prodding physicians to be more attentive to patients’ rights regarding decisionmaking authority. Such prodding, as I have already suggested, is necessary because the idea that patients have rights to autonomy and self-determination has been an alien one throughout the history of medical practice. Ultimately, medicine and not law must formulate a doctrine of informed consent which is responsive not only to the proddings of law but also to the realities of medical practice (i.e., to the complex caretaking and being-taken-care-of interactions that are the essence of all interactions between patients and their physicians). Finally, I shall argue, as I have already noted, that greater emphasis has to be given to disclosure rather than consent

and, therefore, that the inadequacies in current disclosure practices are to begin with the greater obstacle to fashioning an informed consent doctrine which is not a charade.

Guido will soon be a judge on the United States Court of Appeals for the Second Circuit. He, of course, will often return to Yale Law School and, thus, this essay is not written in the spirit of saying farewell to him but of expressing my admiration, at a decisive moment in his professional life, to a wonderful person who over the last thirty-six years has meant so much to me and to my school. I can give him no better present than my thoughts on a topic in which we share a common interest. I hope that in the informed consent cases which will surely come before him, he will address some of my concerns about the persisting inadequacies in the physician-patient decisionmaking process.

I. The Pre-History of Informed Consent in Medicine

The idea that, prior to any medical intervention, physicians must seek their patients' informed consent was introduced into American law in a brief paragraph in a 1957 state court decision, and then elaborated on in a lengthier opinion in 1960. The emerging legal idea that physicians were from now on obligated to share decisionmaking authority with their patients shocked the medical community, for it constituted a radical break with the silence that had been the hallmark of physician-patient interactions throughout the ages. Thirty-five years are perhaps not long enough for either law or medicine to resolve the tension between legal theory and medical practice, particularly since judges were reluctant to face up to implications of their novel doctrine, preferring instead to remain quite deferential to the practices of the medical profession.

Viewed from the perspective of medical history, the doctrine of informed consent, if taken seriously, constitutes a revolutionary break with customary practice. Thus, I must review, albeit all too briefly, the history of doctor-patient communication. Only then can one appreciate how unprepared the medical profession was to heed these new legal commands. But there is more: Physicians could not easily reject what law had begun to impose on them, because they recognized intuitively that the radical transformation of medicine since the age of medical science made it possible, indeed imperative, for a doctrine of informed consent to emerge.

Yet, bowing to the doctrine did not mean accepting it. Indeed, physicians could not accept it because, for reasons I shall soon explore, the nature of informed consent has remained in the words of Churchill, “an enigma wrapped in a mystery.”

Throughout the ages physicians believed that they should make treatment decisions for their patients. This conviction inheres in the Hippocratic Oath: “I swear by Apollo and Aesculepius [that] I will follow that system of regimen which according to my ability and judgment I consider for the benefit of my patients . . .”12 The patient is not mentioned as a person whose ability and judgment deserve consideration. Indeed, in one of the few references to disclosure in the Hippocratic Corpus, physicians are admonished “to [conceal] most things from the patient while attending to him; [to] give necessary orders with cheerfulness and serenity, . . . revealing nothing of the patient’s future or present condition.”13 When twenty-five centuries later, in 1847, the American Medical Association promulgated its first Code of Ethics, it equally admonished patients that their “obedience . . . to the prescriptions of [their] physician should be prompt and implicit. [They] should never permit [their] own crude opinions . . . to influence [their] attention to [their physicians].”14

The gulf separating doctors from patients seemed unbridgeable both medically and socially. Thus, whenever the Code did not refer to physicians and patients as such, the former were addressed as “gentlemen” and the latter as “fellow creatures.” To be sure, caring for patients’ medical needs and “abstain[ing] from whatever is deleterious and mischievous”15 was deeply imbedded in the ethos of Hippocratic medicine. The idea that patients were also “autonomous” human beings, entitled to being partners in decisionmaking, was, until recently, rarely given recognition in the lexicon of medical ethics. The notion that human beings possess individual human rights, deserving of respect, of course, is of recent origin. Yet, it antedates the twentieth century and therefore could have had an impact on the nature and quality of the physician-patient relationship.

It did not. Instead, the conviction that physicians should decide what is best for their patients, and, therefore, that the authority and power to do so should remain vested in them, continued to have a deep hold on the

15. Hippocrates, supra note 12, at 301.
practices of the medical profession. For example, in the early 1950s the influential Harvard sociologist Talcott Parsons, who echoed physicians' views, stated that the physician is a technically competent person whose competence and specific judgments and measures cannot be competently judged by the layman and that the latter must take doctors' judgments and measures on 'authority'.

The necessity for such authority was supported by three claims:

First, physicians' esoteric knowledge, acquired in the course of arduous training and practical experience, cannot be comprehended by patients. While it is true that this knowledge, in its totality, is difficult to learn, understand and master, it does not necessarily follow that physicians cannot translate their esoteric knowledge into language that comports with patients' experiences and life goals (i.e., into language that speaks to quality of future life, expressed in words of risks, benefits, alternatives and uncertainties). Perhaps patients can understand this, but physicians have had too little training and experience with, or even more importantly, a commitment to, communicating their "esoteric knowledge" to patients in plain language to permit a conclusive answer as to what patients may comprehend.

Second, patients, because of their anxieties over being ill and consequent regression to childlike thinking, are incapable of making decisions on their own behalf. We do not know whether the childlike behavior often displayed by patients is triggered by pain, fear, and illness, or by physicians' authoritarian insistence that good patients comply with doctors' orders, or by doctors' unwillingness to share information with patients. Without providing such information, patients are groping in the dark and their stumbling attempts to ask questions, if made at all, makes them appear more incapable of understanding than they truly are.

We know all too little about the relative contributions which being ill, being kept ignorant, or being considered incompetent make to these regressive manifestations. Thus, physicians' unexamined convictions easily become self-fulfilling prophesies. For example, Eric Cassell has consistently argued that illness robs patients of autonomy and that only subsequent to the act of healing is autonomy restored. While there is some truth to these contentions, they overlook the extent to which doctors can restore autonomy prior to the act of healing by not treating patients as

children but as adults whose capacity for remaining authors of their own fate can be sustained and nourished. Cassell’s views are reminiscent of Dostoyevsky’s Grand Inquisitor who proclaimed that “at the most fearful moments of life,” mankind is in need of “miracle, mystery and authority.” While, in this modern age, a person’s capacity and right to take responsibility for his or her conduct has been given greater recognition than the Grand Inquisitor was inclined to grant, it still does not extend to patients. In the context of illness, physicians are apt to join the Grand Inquisitor at least to the extent of asserting that, while patients, they can only be comforted through subjugation to miracle, mystery and authority.

Third, physicians’ commitment to altruism is a sufficient safeguard for preventing abuses of their professional authority. While altruism, as a general professional commitment, has served patients well in their encounters with physicians, the kind of protection it does and does not provide has not been examined in any depth. I shall have more to say about this later on. For now, let me only mention one problem: Altruism can only promise that doctors will try to place their patients’ medical needs over their own personal needs. Altruism cannot promise that physicians will know, without inquiry, patients’ needs. Put another way, patients and doctors do not necessarily have an identity of interest about matters of health and illness. Of course, both seek restoration of health and cure, and whenever such ends are readily attainable by only one route, their interests indeed may coincide.

In many physician-patient encounters, however, cure has many faces and the means selected affect the nature of cure in decisive ways. Thus, since quality of life is shaped decisively by available treatment options (including no treatment), the objectives of health and cure can be pursued in a variety of ways. Consider, for example, differences in value preferences between doctors and patients about longevity versus quality of remaining life. Without inquiry, one cannot presume identity of interest. As the surgeon Nuland cogently observed: “A doctor’s altruism notwithstanding, his agenda and value system are not the same as those of the patient. That is the fallacy in the concept of beneficence so cherished by many physicians.”

II. The Age of Medical Science and Informed Consent

During the millennia of medical history, and until the beginning of the twentieth century, physicians could not explain to their patients, or — from the perspective of hindsight — to themselves, which of their treatment recommendations were curative and which were not. To be sure, doctors, by careful bedside observation, tried their level best “to abstain from what is deleterious and mischievous,” to help if they could, and to be available for comfort during the hours, days or months of suffering. Doing more curatively, however, only became possible with the advent of the age of medical science. The introduction of scientific reasoning into medicine, aided by the results of carefully conducted research, permitted doctors for the first time to discriminate more aptly between knowledge, ignorance and conjecture in their recommendations for or against treatment. Moreover, the spectacular technological advances in the diagnosis and treatment of disease, spawned by medical science, provided patients and doctors with ever-increasing therapeutic options, each having its own particular benefits and risks.

Thus, for the first time in medical history it is possible, even medically and morally imperative, to give patients a voice in medical decisionmaking. It is possible because knowledge and ignorance can be better specified; it is medically imperative because a variety of treatments are available, each of which can bestow great benefits or inflict grievous harm; it is morally imperative because patients, depending on the lifestyle they wish to lead during and after treatment, must be given a choice.

All this seems self-evident. Yet, the physician-patient relationship — the conversations between the two parties — was not altered with the transformation of medical practice during the twentieth century. Indeed, the silence only deepened once laboratory data were inscribed in charts and not in patients’ minds, once machines allowed physicians’ eyes to gaze not at patients’ faces but at the numbers they displayed, once x-rays and electrocardiograms began to speak for patients’ suffering rather than their suffering voices.

What captured the medical imagination and found expression in the education of future physicians, was the promise that before too long the diagnosis of patients’ diseases would yield objective, scientific data to the point of becoming algorithms. Treatment, however, required subjective data from patients and would be influenced by doctors’ subjective judgments. This fact was overlooked in the quest for objectivity. Also overlooked was the possibility that greater scientific understanding of the
nature of disease and its treatment facilitated better communication with patients. In that respect contemporary Hippocratic practices remained rooted in the past.

III. THE IMPACT OF LAW

The impetus for change in traditional patterns of communication between doctors and patients came not from medicine but from law. In a 1957 California case, and a 1960 Kansas case, judges were astounded and troubled by these undisputed facts: That without any disclosure of risks, new technologies had been employed which promised great benefits but also exposed patients to formidable and uncontrollable harm. In the California case, a patient suffered a permanent paralysis of his lower extremities subsequent to the injection of a dye, sodium urokan, to locate a block in the abdominal aorta. In the Kansas case, a patient suffered severe injuries from cobalt radiation, administered, instead of conventional x-ray treatment, subsequent to a mastectomy for breast cancer. In the latter case, Justice Schroeder attempted to give greater specifications to the informed consent doctrine, first promulgated in the California decision: "To disclose and explain to the patient, in language as simple as necessary, the nature of the ailment, the nature of the proposed treatment, the probability of success or of alternatives, and perhaps the risks of unfortunate results and unforeseen conditions within the body."22

From the perspective of improved doctor-patient communication, or better, shared decisionmaking, the fault lines inherent in this American legal doctrine are many:

One: The common law judges who promulgated the doctrine restricted their task to articulating new and more stringent standards of liability whenever physicians withheld material information that patients should know, particularly in light of the harm that the spectacular advances in medical technology could inflict. Thus, the doctrine was limited in scope, designed to specify those minimal disclosure obligations that physicians must fulfill to escape legal liability for alleged non-disclosures. Moreover, it was shaped and confined by legal assumptions about the objectives of the laws of evidence and negligence, and by economic philosophies as to

22. Id. at 1106.
who should assume the financial burdens for medical injuries sustained by patients.

Even though the judges based the doctrine on “Anglo-American law[s] . . . premise of thorough-going self-determination,” as the Kansas court put it, or on “the root premise . . . fundamental in American jurisprudence that ‘every human being of adult years and sound mind has a right to determine what shall be done with his own body,’” as the Circuit Court for the District of Columbia put it in a subsequent opinion, the doctrine was grounded not in battery law (trespass), but in negligence law. The reasons are many. I shall only mention a compelling one: Battery law, based on unauthorized trespass, gives doctors only one defense—that they have made adequate disclosure. Negligence law, on the other hand, permits doctors to invoke many defenses, including “the therapeutic privilege” not to disclose when in their judgment, disclosure may prove harmful to patients’ welfare.

Two recent opinions illustrate the problems identified here. First, in a rare opinion, the Supreme Court of Pennsylvania reconfirmed its adherence to the minority view among American jurisdictions that battery, not negligence, is the appropriate cause of action whenever lack of informed consent is alleged. The court held that whenever “the patient . . . demonstrated, and the jury found, that he was not advised of . . . material facts, risks, complications and alternatives to surgery which a reasonable man would have considered significant in deciding whether to have the operation . . . the causation inquiry ends. The sole issue remaining [is] a determination of damages.” Earlier in its opinion, the court quoted, with approval, a prior Pennsylvania decision:

[W]here a patient is mentally and physically able to consult about his condition, in the absence of an emergency, the consent of the patient is “a prerequisite to a surgical operation by his physician, and an operation without the patient’s consent is a technical assault.”

Second, the Court of Appeals of California, in a ground-breaking opinion, significantly reduced the scope of the therapeutic privilege by requiring that in instances of hopeless prognosis (the most common situation in which the privilege has generally been invoked) the patient be provided

23. Id. at 1104.
with such information by asking, "If not the physician's duty to disclose a terminal illness, then whose?"\textsuperscript{27} The duty to disclose prognosis had never before been identified specifically as one of the disclosure obligations in an informed consent opinion.

Thus, the appellate court's ruling constituted an important advance. It established that patients have a right to make decisions not only about the fate of their bodies but about the fate of their lives as well. The California Supreme Court, however, reversed. In doing so, the court made too much of an issue raised by the plaintiffs that led the appellate court to hold that doctors must disclose "statistical life expectancy information."\textsuperscript{28} To be sure, disclosure of statistical information is a complex problem, but in focusing on that issue, the supreme court's attention was diverted from a more important new disclosure obligation promulgated by the appellate court: the duty to inform patients of their dire prognosis. The supreme court did not comment on that obligation. Indeed, it seemed to reverse the appellate court on this crucial issue by reinforcing the considerable leeway granted physicians to invoke the therapeutic privilege exception to full disclosure: "We decline to intrude further, either on the subtleties of the physician-patient relationship or in the resolution of claims that the physician's duty of disclosure was breached, by requiring the disclosure of information that may or may not be indicated in a given treatment context."\textsuperscript{29}

Two: The doctrine of informed consent was not designed to serve as a medical blueprint for interactions between physicians and patients. The medical profession still faces the task of fashioning a "doctrine" that comports with its own vision of doctor-patient communication and that is responsive both to the realities of medical practices in an age of science and to the commands of law. As I said years ago,

\begin{quote}
[T]ranslating the ingredients of [the informed consent] process into legal and useful medical prescriptions that respect patients' wishes to maintain and surrender autonomy, as well as physicians' unending struggles with omnipotence and impotence in the light of medical uncertainty, is a difficult task [which the medical profession] has not pursued ... in any depth.\textsuperscript{30}
\end{quote}

Thus, disclosure practices only changed to the extent of physicians dis-

\textsuperscript{28} Arato, 11 Cal. Rptr. 2d at 177.
\textsuperscript{29} Arato, 858 P.2d at 607.
\textsuperscript{30} KATZ, supra note 9, at 84.
closing more about the risks of a proposed intervention in order to escape legal liability.

Three: Underlying the legal doctrine there lurks a broader assumption which has neither been given full recognition by judges nor embraced by physicians. The underlying idea is this: That from now on patients and physicians must make decisions jointly, with patients ultimately deciding whether to accede to doctors' recommendations. In The Cancer Ward, Solzhenitsyn captured, as only a novelist can, the fears that such an idea engenders. When doctor Ludmilla Afanasyevna was challenged by her patient, Oleg Kostoglotov, about physicians' rights to make unilateral decisions on behalf of patients, Afanasyevna gave a troubled, though unequivocal, answer: "But doctors are entitled to the right — doctors above all. Without that right, there'd be no such thing as medicine."31

If Afanasyevna is correct, then patients must continue to trust doctors silently. Conversation, to comport with the idea of informed consent, ultimately requires that both parties make decisions jointly and that their views and preferences be treated with respect. Trust, based on blind faith — on passive surrender to oneself or to another — must be distinguished from trust that is earned after having first acknowledged to oneself and then shared with the other what one knows and does not know about the decision to be made. If all of that had been considered by physicians, they would have appreciated that a new model of doctor-patient communication, that takes informed consent seriously required a radical break with current medical disclosure practice.

Four: The idea of joint decisionmaking is one thing, and its application in practice another. To translate theory into practice cannot be accomplished, as the Judicial Council of the American Medical Association attempted to do in one short paragraph. The Judicial Council stated that "[t]he patient should make his own determination on treatment. Informed consent is a basic social policy . . . ."32 To translate social policy into medical policy is an inordinately difficult task. It requires a reassessment of the limits of medical knowledge in the light of medical uncertainty, a reassessment of professional authority to make decisions for patients in light of the consequences of such conduct for the well-being of patients, and a reassessment of the limits of patients' capacities to assume responsibility for choice in the light of their ignorance about medical mat-

ters and their anxieties when ill. Turning now to these problems, I wish to highlight that, in the absence of such reassessments, informed consent will remain a charade, and joint decisionmaking will elude us.

IV. Barriers to Joint Decisionmaking

A. Medical Uncertainty

The longer I reflect about doctor-patient decisionmaking, the more convinced I am that in this modern age of medical science, which for the first time permits sharing with patients the uncertainties of diagnosis, treatment, and prognosis, the problem of uncertainty poses the most formidable obstacle to disclosure and consent. By medical uncertainty I mean to convey what the physician Lewis Thomas observed so eloquently, albeit disturbingly:

The only valid piece of scientific truth about which I feel totally confident is that we are profoundly ignorant about nature. . . . It is this sudden confrontation with the depth and scope of ignorance that represents the most significant contribution of twentieth-century science to the human intellect. We are, at last facing up to it. In earlier times, we either pretended to understand . . . or ignored the problem, or simply made up stories to fill the gap.33

Alvan Feinstein put this in more concrete language: “Clinicians are still uncertain about the best means of treatment for even such routine problems as . . . a fractured hip, a peptic ulcer, a stroke, a myocardial infarction. . . . At a time of potent drugs and formidable surgery, the exact effects of many therapeutic procedures are dubious or shrouded in dissension.”34

Medical uncertainty constitutes a formidable obstacle to joint decisionmaking for a number of reasons: Sharing uncertainties requires physicians to be more aware of them than they commonly are. They must learn how to communicate them to patients and they must shed their embarrassment over acknowledging the true state of their own and of medicine’s art and science. Thus, sharing uncertainties requires a willingness to admit ignorance about benefits and risks; to acknowledge the existence of alternatives, each with its own known and unknown consequences; to eschew one single authoritative recommendation; to consider

carefully how to present uncertainty so that patients will not be over-
whelmed by the information they will receive; and to explore the crucial
question of how much uncertainty physicians themselves can tolerate
without compromising their effectiveness as healers.

To so conduct oneself is most difficult. For, once doctors, on the basis
of their clinical experience and knowledge, conclude which treatment is
best, they tend to disregard, if not reject, the view of other colleagues
who treat the same condition differently. Consider the current contro-
versy over the management of localized prostate cancer: surgery, radia-
tion or watchful waiting. Some of the physicians involved in the debate
are not even willing to accept that uncertainty exists, or at least they mini-
mize its relevance to choice of treatment. Most who advocate treatment
strongly prefer one type over another based on professional specializa-
tion (radiologists tend to recommend radiation; surgeons surgery).

Moreover, acknowledgement of uncertainty is undermined by the
threat that it will undermine doctors’ authority and sense of superiority.
As Nuland put it, to feel superior to those dependent persons who are the
sick, is after all a motivating factor that often influences their choice of
medicine as a profession. All of this suggests that implementation of
the idea of informed consent is, to begin with, not a patient problem but a
physician problem.

B. Patient Incompetence

Earlier, I touched on physicians’ convictions that illness and medicine’s
esoteric knowledge rob patients of the capacity to participate in decision-
making. Yet we do not know whether this is true. The evidence is com-
promised by the groping, half-hearted, and misleading attempts to inform
patients about uncertainty and other matters which can make doctors’
communications so confusing and incomprehensible. If patients then ap-
ppear stupid and ignorant this should come as no surprise; nor should pa-
tients’ resigned surrender to this dilemma: “You are the doctor, you
decide.”

It is equally debatable, as Thomas Duffy has contended, that
“[p]aternalism exists in medicine . . . to fulfill a need created by illness.” It led him to argue, echoing Cassell, that “obviously autonomy cannot

35. Gerald W. Chodak et al., Results of Conservative Management of Clinically Local-
37. Thomas P. Duffy, Agamemnon’s Fate and the Medical Profession, 9 W. NEW ENG.
function as the cornerstone of the doctor-patient relationship [since] the impact of disease on personal integrity results in the patient's loss of autonomy. . . . In the doctor-patient relationship, the medical profession should always err on the side of beneficence."\(^\text{38}\) If Duffy is correct, however, then informed consent is \textit{ab initio} fatally compromised.

\section*{C. Patient Autonomy}

Duffy's invocation of beneficence as the guiding principle is deeply rooted in the history of Hippocratic medicine. It finds expression in the ancient maxim: \textit{primum non nocere}, above all do no harm, with "harm" remaining undefined but in practice being defined only as physical harm. Before presenting my views on the controversy over the primacy of autonomy or beneficence, let me briefly define their meaning.

In their authoritative book \textit{Principles of Biomedical Ethics}, Thomas Beauchamp and James Childress defined these principles:

\begin{quote}
Autonomy is a form of personal liberty of action where the individual determines his or her own course of action in accordance with a plan chosen by himself or herself. [Respect for individuals as autonomous agents entitles them] to such autonomous determinations without limitation on their liberty being imposed by others.\(^\text{39}\)
\end{quote}

Beneficence, on the other hand,

\begin{quote}
[r]equires not only that we treat persons autonomously and that we refrain from harming them, but also that we contribute to their welfare including their health. [Thus the principle asserts] the duty to help others further their important and legitimate interests . . . to \textit{confer} benefits and actively to prevent and remove harms . . . [and] to \textit{balance} possible goods against the possible harms of an action.\(^\text{40}\)
\end{quote}

Beauchamp and Childress' unequivocal and strong postulate on autonomy contrasts with the ambiguities contained in their postulate on beneficence. What do they mean by "benefits" and "harms" that allow invocation of beneficence? Do they mean only benefits and harms to patients' physical integrity, or to their dignitary integrity as choice-making individuals as well? Furthermore, what degree of discretion and li-

\begin{flushright}
38. \textit{Id.} at 30.
\end{flushright}
cense is permissible in the duty “to balance?” I have problems with balancing unless it is resorted to only as a rare exception to respect for autonomy. While human life is, and human interactions are, too complex to make any principle rule absolute, any exceptions must be rigorously justified.

I appreciate that mine is a radical proposal and constitutes a sharp break with Hippocratic practices. If informed consent, however, is ever to be based on the postulate of joint decisionmaking, the obligation “to respect the autonomous choices and actions of others,” as Childress has put it, must be honored. Otherwise, informed consent is reduced to doctors providing more information but leaving decisionmaking itself to the authority of physicians.

As one physician once told me, echoing only an all too prevalent belief (and he was a physician allegedly deeply committed to informed consent), “I must first make the judgment which treatment alternative is best for patients, and only after I have exercised that professional judgment, will I discuss the risks and benefits of the recommended treatment.” This story illustrates the emphasis doctors place on risk disclosures rather than alternatives. The latter, however, is more crucial to joint decisionmaking than the former. Such a view, however, again encounters the issue of disclosure of medical uncertainty inherent in any forthright discussion of treatment alternatives. Physicians remain most reluctant to acknowledge uncertainty to themselves, and even more to their patients.

V. RESPECT FOR AUTONOMY

It should be evident by now that physicians must embark on a prolonged period of self-examination about how to interact with patients in new ways in an age of medical science and informed consent. Physicians must cease to complain about lawyers forcing them “to do silly things.” Whenever doctors do so, they often observe that they can easily present their disclosures in ways that lead patients to agree with what they had thought to be the best alternative in the first place. This contention is a correct assessment of what transpires in customary practices that continue to eschew joint decisionmaking. Therefore, as I have already suggested, informed consent in today’s world, is largely a charade which misleads patients into thinking that they are making decisions when indeed they are not.

Any meaningful change in Hippocratic decisionmaking practices first requires a new and revolutionary commitment to one principle: that physicians must respect patients as autonomous persons. The most crucial reason for my placing such high value on autonomy and self-determination is because doing so safeguards, as nothing else can, the recognition by the other that the person before him or her is as much a person as he or she is. Beneficence can readily reduce persons to non-persons by “taking care of them” in all of the many not only caring, but also, non-caring meanings of this phrase.

Before continuing, I must interject a few comments about my usage of the concept of autonomy. The principle of autonomy has been subjected to criticism because its invocation can so readily consign human beings to abstract categories which defy reality. I wrote about this problem in my book _The Silent World of Doctor and Patient:_ “Abstract principles tend to express generalizations about conduct that are ill-suited for application to actual cases in which human capacities to exercise rights must be considered.” Thus, I spoke instead about “psychological autonomy,” to distinguish my conception of autonomy, for example, from that of Kant who restricted it to individuals’ capacities to reason without any reference to their emotional life and their dependence on the external world. Instead, I wanted to convey by psychological autonomy, or better by respect for psychological autonomy, that human autonomy is fragile and that its optimal exercise requires both physicians and patients to pay caring attention to their capacities and incapacities for self-determination. In their interactions with one another, they must therefore through obligatory conversation, support and enhance their real, though precarious, endowment for reflective thought.

My views on psychological autonomy have been criticized as reintroducing paternalism into the physician-patient relationship. In particular, critics have argued that my emphasis on the obligation of patients to participate in such conversations constitutes an invasion of their privacy. While the criticism has merit, without such an obligation, autonomy is reduced to an abstraction that is inattentive to the psychological reality of both the strength and fragility of the human mind.

My views have also been misunderstood to require a lengthy, even “psychoanalytic,” exploration of patients’ minds. This was not my intention. I merely wished to suggest that it is possible to go to some length of subjecting thoughts and contemplated actions to clarification through dia-

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42. Katz, _supra_ note 9, at 107.
logue which, in turn, may lead to a better understanding of what is at stake in the medical decisions to be made. Doing more is impossible and doing that much may not persuade patients to choose a course of action that is "in their best interests." But, as Justice Stevens once put it, "[I]t is far better to permit some individuals to make incorrect decisions than to deny all individuals the right to make decisions that have a profound effect upon their destiny."43

In such conversations the principle of beneficence, often invoked as a counterpoise to autonomy, finds its rightful but delimited expression. Beneficence, in my view, requires physicians to enhance patients' capacities to arrive at the best autonomous choices they are capable of making by clearly and respectfully providing them with the information they need. The inherent tensions between the two principles, therefore, must be resolved, as I have already suggested, by giving primacy to autonomy. My reasons are twofold: (1) Autonomy assures that ultimate authority about treatment decisions resides with patients, including the decision to authorize doctors to decide for them. Since it is their bodily integrity that is at stake, no one but they can decide what should be done for them. (2) In the past, beneficence has served too unquestionably as justification for the unilateral exercise of physicians' authority to make decisions on behalf of patients. Although in rare circumstances it may trump autonomy, beneficence should only ensure that physicians will caringly assist patients to make their own choices, informed by the clarification physicians can provide about the medical consequences of the available options, particularly, of course, the consequences of patients' preferences for an option with which their doctors disagree.

Adherence to the principle of autonomy, in the ways I have defined it, demands that physicians respect patients' autonomy as choice-making individuals, and that their ultimate choices (except under the rarest and most carefully defined circumstances) be honored. It is based on the assumption that many patients are capable of comprehending what they need to know in order to decide what is best for themselves and that, therefore, they must be treated as adults possessed of the capacity for self-determination.

It is beyond the scope of this essay to explore decisionmaking between physicians and patients incompetent by virtue of severe mental illness, brain damage, or age. Throughout, I have limited my inquiry to doctors'

interactions with competent patients often considered “incompetent” by doctors for reasons set forth above. To be sure, decisions by patients, like those of all human beings, are influenced by rational and irrational thoughts, rational and irrational emotions and rational and irrational judgments derived from the world of knowledge, experience and beliefs in which they have lived their lives. Respect for patient autonomy only postulates that patients, like human beings generally, have considerable capacity to listen, learn and reflect; that they can and must learn a great deal from doctors about the world of medicine as it affects their disease and dis-ease; and that they can choose and act better on their own behalf than doctors can act for them.

VI. THE CURRENT STATE OF PHYSICIAN-PATIENT DECISIONMAKING

In his recent book, entitled How We Die, Sherwin Nuland, a distinguished surgeon, reflects with profundity and insight on his lifelong interactions with patients. In a chapter on cancer and its treatment he speaks movingly about “death belong[ing] to the dying and to those who love them.” Yet, that privilege is often wrested from them when,

[d]ecisions about continuation of treatment are influenced by the enthusiasm of the doctors who propose them. Commonly, the most accomplished of the specialists are also the most convinced and unyielding believers in biomedicine’s ability to overcome the challenge presented by a pathological process. . . . [W]hat is offered as objective clinical reality is often the subjectivity of a devout disciple of the philosophy that death is an implacable enemy. To such warriors, even a temporary victory justifies the laying waste of the fields in which a dying man has cultivated his life.

Looking back at his work, he concludes that “more than a few of my victories have been Pyrrhic. The suffering was sometimes not worth the success. . . . [H]ad I been able to project myself into the place of the family and the patient, I would have been less often certain that the desperate struggle should be undertaken.” In his view, a surgeon,

[t]hough he be kind and considerate of the patient he treats . . . allows himself to push his kindness aside because the seduction of The Riddle [the quest for diagnosis and cure] is so strong and

44. SHERWIN B. NULAND, HOW WE DIE 265 (1994).
45. Id.
46. Id. at 266.
the failure to solve it renders him so weak. [Thus, at times he convinces] patients to undergo diagnostic or therapeutic measures at a point in illness so far beyond reason that The Riddle might better have remained unsolved.\textsuperscript{47}

Speaking then about the kind of doctor he will seek out when afflicted with a major illness, Nuland does not expect him to “understand my values, my expectations for myself . . . my philosophy of life. \textit{That is not what he is trained for and that is not what he will be good at.}”\textsuperscript{48} Doctors can impart information, but “[i]t behooves every patient to study his or her own disease and learn enough about it. [Patients] should no longer expect from so many of our doctors what they cannot give.”\textsuperscript{49}

Nuland’s views, supported by a great many poignant clinical vignettes, sensitively and forthrightly describe the current state of physician-patient decisionmaking, so dominated by physicians’ judgments as to what is best. He presents many reasons for this state of affairs. One is based on doctors’ “fear of failure:”

A need to control that exceeds in magnitude what most people would find reasonable. When control is lost, he who requires it is also a bit lost and so deals badly with the consequences of his impotence. In an attempt to maintain control, a doctor, usually without being aware of it, convinces himself that he knows better than the patient what course is proper. He dispenses only as much information as he deems fit, thereby influencing a patient’s decision-making in ways he does not recognize as self-serving.\textsuperscript{50}

I have presented Nuland’s observations at some length because they illustrate and support my contentions that joint decisionmaking between doctors and patients still eludes us. My critics had claimed earlier that my work on informed consent was dated because informed consent had become an integral aspect of the practice of medicine. In the paperback edition of \textit{The Silent World of Doctor and Patient}, I argued that they have dismissed too lightly my central arguments:

\begin{quote}
[T]hat meaningful collaboration between physicians and patients cannot become a reality until physicians have learned (1) how to treat their patients not as children but as the adults they are; (2) how to distinguish between their ideas of the best treatment and their patients’ ideas of what is best; (3) how to ac-
\end{quote}

\textsuperscript{47} Id. at 249.
\textsuperscript{48} Id. at 266 (emphasis added).
\textsuperscript{49} Id. at 260.
\textsuperscript{50} Id. at 258.
knowledge to their patients (and often to themselves as well) their ignorance and uncertainties about diagnosis, treatment, and prognosis; [and to all this, I now want to add, (4) how to explain to patients the uncertainties inherent in the state of the art and science of medicine which otherwise permits doctors on the basis of their clinical experience to leave unacknowledged that their colleagues on the basis of their clinical experience have different beliefs as to which treatment is best].

Nuland pleads for the resurrection of the family doctor because he believes that the specialist is inadequate to the task of shouldering the burdens of decision with his patients. About this I differ with him. I believe that physicians (and surgeons as well) can, and must, learn to converse with patients in the spirit of joint decisionmaking. Physicians can and must learn to appreciate better than they do now that the principle of respect for person speaks to the caring commitment of physicians in old and new ways: Old in that it highlights the ancient and venerable medical duty not to abandon patients, and new by requiring doctors to communicate with them and remain at their sides, not only while their bodies are racked with pain and suffering but also while their minds are beset by fear, confusion, doubt and suffering over decisions to be made; also new in that implementation of the principle of psychological autonomy imposes the obligations on physicians both to invite, and respond to, questions about the decisions to be made, and to do so by respecting patients’ ultimate choices, a new aspect of the duty to care.

The moral authority of physicians will not be undermined by this caring view of interacting with patients. Doctors’ authority resides in the medical knowledge they possess, in their capacity to diagnose and treat, in their ability to evaluate what can be diagnosed and what cannot, what is treatable and what is not, and what treatment alternatives to recommend, each with its own risks and benefits and each with its own prognostic implications as to cure, control, morbidity, exacerbation or even death.

The moral authority of physicians resides in knowing better than others the certainties and the uncertainties that accompany diagnosis, treatment, prognosis, health and disease, as well the extent and the limits of their scientific knowledge and scientific ignorance. Physicians must learn to face up to and acknowledge the tragic limitations of their own professional knowledge, their inability to impart all their insights to all patients, and their own personal incapacities — at times more pronounced than

52. Nuland, supra note 44, at 266.
others — to devote themselves fully to the needs of their patients. They
must learn not to be unduly embarrassed by their personal and profes-
sional ignorance and to trust their patients to react appropriately to such
acknowledgment. From all this it follows that ultimately the moral au-
thority of physicians resides in their capacity to sort out with patients the
choices to be made.

It is in this spirit that duty and caring become interwoven. Bringing
these strands together imposes upon physicians the duty to respect pa-
tients as persons so that care will encompass allowing patients to live
their lives in their own self-willed ways. To let patients follow their own
lights is not an abandonment of them. It is a professional duty that, how-
ever painful, doctors must obey.

Without fidelity to these new professional duties, true caring will elude
physicians. There is much new to be learned about caring that in decades
to come will constitute the kind of caring that doctors in the past have
wished for but have been unable to dispense, and that patients may have
always yearned for.

I do not know whether my vision of a new physician-patient relation-
ship defies medical reality. Thus, I may be wrong and I am willing to
entertain this possibility as long as my critics are willing to admit that they
too may be wrong. As a profession we have never examined and tested in
a committed manner what I have proposed. It is this fact which, in conclu-
sion, I want to highlight. For, I believe that in this age of medical science
and informed consent the category of patient is in need of a radical recon-
ceptualization. Throughout medical history, patients have been viewed as
passive, ignorant persons whose welfare was best protected by their fol-
lowing doctors' orders, and physicians and patients were socialized to in-
teract with one another on that basis. Throughout this essay, I have
argued that such a view of the physician-patient relationship was dictated
by doctors' inability to explain to themselves what was therapeutic and
what was not in the practice of medicine. The advent of the age of medi-
cal science has changed all that and for the first time in medical history
doctors now can distinguish better between knowledge, ignorance and
conjecture. In turn, this permits physicians to take patients into their
confidence.

Finally, my purpose in writing this essay is twofold: (1) To argue,
notwithstanding any theories of tort law and cost containment to the con-
trary,53 that patients must ultimately be given the deciding vote in matters

that effect their lives; and (2) to suggest that informed consent will remain a fairy tale as long as the idea of joint decisionmaking, based on a commitment to patient autonomy and self-determination, does not become an integral aspect of the ethos of medicine and the law of informed consent. Until then, physicians, patients and judges can only deceive themselves or be deceived about patients having a vital voice in the medical decisionmaking process. Of course, there are alternatives to joint decisionmaking. One that I have briefly explored elsewhere suggested that we need a number of informed (and uninformed) consent doctrines depending on the nature of the decisions to be made, with the implication that only in certain medical contexts must informed consent rise to the rigor advanced in this essay.54 Another alternative is to fashion an informed consent doctrine for law and medicine that is not based on "[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."55 It is not a road on which I would like to travel and thus, I leave that task to others. It is important that those who disagree with me set forth their premises about who decides what; otherwise physicians and patients are condemned to interact with one another, under the rubric of what is now called "informed consent," by deception of both self and the other.
