

PHYSICIAN-PATIENT ENCOUNTERS "ON A DARKLING PLAIN"

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The publication of this volume fulfills one of my fondest expectations. As I wrote in the introduction to *The Silent World of Doctor and Patient*;¹

[the] ultimate purpose [of my book] is to initiate a more enlightened debate about the respective rights, duties, and needs of physicians and patients in their intimate, anxiety-producing, and fateful encounters with one another. . . . The problems of . . . greater patient participation in the medical decision-making process . . . deserve study and their in-depth analysis must be extended beyond where I leave off. . . . [M]any additional leads need to be pursued. In this book I have been unable to explore any to their depth. Instead, I have tried to identify as many issues as possible and to pursue them for some distance (pp. xiii, xix, xx).

The editors of the *Western New England Law Review* responded to my hopes and I am grateful to them for the loving care with which they executed this project.

The largely unexplored and controversial issues that I identify in my book have been neglected for too long. Among these issues, one is most basic: my assertions that the responsible practice of medicine demands caring attention not only to patients' physical needs but also to patients' needs to decide how these physical needs are to be satisfied.

The advances in medical science have markedly improved the benefits that patients can derive from diagnostic and therapeutic interventions unheard of only a few decades ago, but these very same advances not only increase opportunities for choice among treatment alternatives but also expose patients to different, and at times considerable, known and unknown risks. Yet, the availability of choice and the danger of inflicting pain and suffering have not moved physicians

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1. J. KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984) [hereinafter Katz].

to consider seriously the question: When must choice be delegated to patients? Instead, physicians still maintain that decisionmaking is their prerogative. However, what was true for the dark ages of medicine, when doctors had little more to offer than caring comfort, is not true for the age of medical science, when doctors' ministrations can both ameliorate and increase suffering.

In these concluding remarks I shall comment on only a few of the symposium's articles in an attempt to pursue further the new leads opened up by their thoughtful critique of my work. I am grateful to these contributors, as well as to the other authors whom I do not mention, for their generous reading of my work. All took seriously my admonition that, if what I have done has merit, it must be extended beyond where I left off.

My book, now three years old, has been cited in many articles and books. Their authors have come almost exclusively from the ranks of non-physicians. I mention this fact to address first one criticism of my work: that my emphasis on physicians' obligations to ensure fidelity to joint decisionmaking was a mistake.² Instead, I should have written a book for patients, if only because doctors would not readily change deeply ingrained convictions without outside pressure.

My critics felt that the focus on physicians' responsibilities not only "[betrays] vestiges of paternalism"³ but also "subtly reinforces the very dependency of the patient [on the physician]."⁴ These concerns have merit. I should have addressed more explicitly what patients can and must do in order to facilitate giving their voices a more respectful hearing in medical decisionmaking. Indeed, I should have said more about patients' responsibility to change existing practices because I already believed then, as I feel even more strongly now, that the medical profession will not readily change habits of silence unless forced to do so by citizen-patients.

However, many reasons—some more important than others—led me to proceed as I did. First and foremost, I wanted to demonstrate that the *idea* of informed consent,⁵ *i.e.*, that patients share the burdens

2. See Baron, *On Knowing One's Chains and Decking Them with Flowers: Limits on Patient Autonomy in "The Silent World of Doctor and Patient,"* 9 W. NEW ENG. L. REV. 31, 40 n.8 (1987); Caplan, *Can We Talk? A Review of Jay Katz, "The Silent World of Doctor and Patient,"* 9 W. NEW ENG. L. REV. 43, 50 (1987).

3. Baron, *supra* note 2, at 40 n.8.

4. *Id.*; Caplan, *supra* note 2, at 50.

5. "[O]ne must draw sharp distinctions between the *legal* doctrine [of informed consent], as promulgated by judges, and the *idea* of informed consent, based on a commitment to individual self-determination." KATZ, *supra* note 1, at xvi.

of decision with their doctors, is, to begin with, not a patient problem but a physician problem. For a considered judgment on patients' capacity for decisionmaking can be rendered only once it is determined that *physicians have the capacity* for conversing with patients about the medical decisions that need to be made. These are problems not only regarding physicians' willingness to learn an unaccustomed new language, and then to talk *with* patients, but also regarding physicians' willingness to confront and come to terms with medical uncertainty (pp. 165-206).

The more I reflect about doctor-patient communication, the more convinced I become 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. For sharing uncertainties requires a willingness to admit ignorance about benefits and risks; to profess to the existence of alternatives, each with its own known and unknown consequences; to eschew one single authoritative recommendation; to consider carefully how to present uncertainties so that patients will not become overwhelmed by the information they are required to know; and to explore the crucial question of how much uncertainty physicians themselves can tolerate without compromising their effectiveness as healers.

Physicians' unexamined conviction that patients, by virtue of their anxieties over being ill and medicine's esoteric knowledge, are incapable of participating in sharing the burdens of decision with their doctors, has made confrontation with uncertainty, at least to the extent of making patients aware of its ubiquitous presence, unnecessary. Thus, the at best groping, half-hearted, thoughtless and misleading attempts to inform patients about uncertainty have made doctors' communications confusing and incomprehensible. No wonder that patients appear stupid and ignorant; no wonder that patients say with resignation: "You are the doctor, you decide."

Second, I also wanted to demonstrate that physicians' unquestioned convictions that non-disclosure serves patients' interests best make it impossible to distinguish between those patients who wish and those who do not wish to be taken into doctors' confidence. It may turn out, once patients are provided with the opportunity of sharing the burdens of decision, that many will decline; but certainly not *all* will. The latter need to be identified so that their voices can be accorded the respect they deserve.

The arguments that patients long ago would have insisted on ex-

exercising their right to participate in decisionmaking had they wished to do so, or that their not doing so is evidence of a felt need, when sick and anxious, to place themselves trustingly into physicians' care, I find unpersuasive. These arguments prove too much.

Patients, when sick, are indeed scared, particularly since illness tends to bring to the surface fears of death and concerns over mortality that otherwise are repressed. These fears and concerns are mobilized even though the particular illness may not be life-threatening. They are also wittingly and unwittingly exploited by physicians in order to ensure compliance.⁶ Death's hovering presence as a third party to physician-patient encounters invites surrender lest, if one offends physicians by imposing on their time or questioning their recommendations, they will be less willing to stand by in the hour of ultimate need and gently ferry patients across the river Styx to their final resting place.

However unjustified such fears may be, they are real fears; fears that are reinforced by physicians' all too common silent, and not so silent, resort to threats of abandonment: "If you are unwilling to accept *my* recommendation, why don't you seek out another physician?" In this climate joint decisionmaking becomes virtually impossible. Physicians must learn to put their patients at ease about the remoteness of death or the unlikelihood of serious consequences to their well-being when such outcomes are not in issue, and about their fears of abandonment, when they question their physicians too closely.

It remains equally unclear to what extent "[p]aternalism exists in medicine . . . to fulfill a need created by illness"⁷ and to what extent it fulfills a need created by physicians. In not dispelling patients' imaginary fears, in keeping patients in the dark about their medical condition, and in treating patients in many other ways as children and not as adults, doctors wittingly and unwittingly reinforce the regressive

6. In *The Silent World of Doctor and Patient*, I state:

The silence that surrounds death, however, does not only reside in the discomfort that the topic engenders. Physicians' silence also serves the purpose of reinforcing their authority over patients. Doctors have an intriguing love-hate relationship with death: It is both their ally and their enemy. In trying to defeat death, physicians are death's adversaries. When physicians borrow the power engendered by patients' fear of death for purposes of control, death is their ally. Doctors often wittingly and unwittingly exploit the anxieties and fears that even benign illness engenders in patients by conveying, if not with words then by demeanor, that not following their orders will accelerate death.

KATZ, *supra* note 1, at 213-14.

7. Duffy, *Agamemnon's Fate and the Medical Profession*, 9 W. NEW ENG. L. REV. 21, 27 (1987).

pull engendered by illness. Thus, the contributions which illness or physicians make to "the need for paternalism" remain unknown. In turn, we do not know whether physician-patient interactions that recognize patients as the adults they are will not reverse the regressive pull that illness also mobilizes.

Third, I also wanted to demonstrate that meaningful conversation between doctors and patients requires physicians to re-examine the ancient notion that they and their patients have an identity of interests in medical matters and that, therefore, physicians can make decisions for patients. Of course, both seek restoration of health and cure and whenever such ends are readily attainable by only one route, their interests indeed do coincide. However, in many physician-patient encounters, cure has many faces and the means selected affect the nature of cure in decisive ways.⁸

Consider, for example, a patient with a fibroid uterus who presents herself with a complaint of intermittent, increased bleeding during menses. Cure can mean a hysterectomy, or reassurance that no dire result will follow from living with the condition, or the employment of various medical means to bring the bleeding at least under partial control. If the last course of treatment is adopted, some of the medical interventions could expose the patient to future, as yet unknown, risks. Beyond that problem, doctors and patients may differ about the value they ascribe to retaining or parting with an organ that has myriads of symbolic meanings. Clinical examples of the multiplicity of ends attainable and means available for the treatment of medical conditions are numerous, a result of the spectacular advances in medical science. Thus, the question: what constitutes cure? Identity of interest about ends and means cannot be assumed. It can be established only through respectful conversation.

The fear that respecting patients' choices may jeopardize a good medical outcome also requires careful reflection. As I have suggested already, what constitutes a good medical outcome is not as readily apparent as is often assumed.⁹ Not only can physicians and patients differ on this question but physicians themselves come to this question with differing convictions. Again, is removal or retention of a uterus

8. For a perceptive discussion of ends and means in lawyer-client relationships, see Spiegel, *Lawyers and Professional Autonomy: Reflections on Corporate Lawyering and the Doctrine of Informed Consent*, 9 W. NEW ENG. L. REV. 139, 145-46, 148 (1987).

9. See Duffy, *supra* note 7, at 30: "A poor medical outcome should not be allowed to evolve due to respect for autonomy." But what is a good medical outcome? When does "the doctor . . . [know what is] best . . . [and when is it] arrogance if he or she adheres to that adage and acts in a patient's behalf . . .?" *Id.* at 24.

for fibroids the “good” medical decision? Is treatment or non-treatment of essential hypertension of moderate degree a “good” medical decision?

My emphasis on patient autonomy and choice does not undermine physicians’ “moral authority.”¹⁰ Physicians’ authority resides in their capacity to heal, not in making decisions for others. While physicians may have needed to usurp decisionmaking authority during the dark ages of medicine, the exercise of such authority has no place in the age of medical science.

Of course, medical practice has “underpinnings of certainty”¹¹—the result of the great scientific advances during the last one hundred years—but science also has made physicians aware of the uncertainties and ignorance that stalk medical practice.¹² Science also has given physicians the capacity to distinguish better between certainty and uncertainty. Moreover, physicians embrace science’s abiding commitment to the search for truth which raises the question: why should not this commitment to truth extend to conversations with patients?

The moral authority of physicians to make decisions on behalf of patients requires a more precise and restrictive definition. In physician-patient interactions there probably is room for some discretion in what to tell and not to tell patients or in making decisions for patients,

10. *But see* Duffy, *supra* note 7, at 25: Katz’s “perception represents a loss of honor for a profession which once was thought to possess moral authority and discretion.”

11. *Id.* at 24. *But see infra* note 12.

12. For example, Lewis Thomas, a physician deeply committed to the practice of scientific medicine, noted:

The only solid piece of scientific truth about which I feel totally confident is that we are profoundly ignorant about nature. Indeed, I regard this as the major discovery of the past hundred years of biology. . . . 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 how things worked or ignored the problem or simply made up stories to fill the gaps.

L. THOMAS, *THE MEDUSA AND THE SNAIL: MORE NOTES OF A BIOLOGY WATCHER* 73-74 (1979).

In a *New York Times* article, Thomas stated:

The scientific method is guesswork, the making up of stories. The difference between this and other imaginative works of the human mind is that science is then obliged to find out whether the guesses are correct, the stories true. Curiosity drives the enterprise, and the open acknowledgment of ignorance. [W]e know very little about nature and we understand even less.

Starting with ourselves, and the life immediately around us, we have lots of homework to do, lots of pride to swallow, lots more ignorance to face, some of it only sensed out of the corner of the eye

Thomas, *How Should Humans Pay Their Way?* *N. Y. Times*, Aug. 24, 1981, at A15, cols. 2-5.

but this discretion must be defined and circumscribed more clearly lest it will continue to be abused.

Why should this moral authority give physicians the right to make choices for patients? Does not this moral authority belong to patients, particularly when choices are available, when each choice is influenced by medical and other value judgments, when the risk-benefit ratio is unclear, and when uncertainty rules medical practice? It is hubris to answer this question by supporting medical authority merely on an assertion of beneficence and altruism.¹³ It is equally dangerous to usurp this authority on the ground that patients' "best interests" demand that doctors assume this responsibility. The history of mankind gives telling evidence of the harm done in the name of "best interest." The "protection" in the name of "best interest," extended to slaves, women, the mentally ill, and juvenile delinquents are examples in point.

However, there is more; for behind physicians' fears of compromising a good medical outcome by acknowledging uncertainty and respecting patient self-determination, lie even greater fears: that patients will halt therapy prematurely and will choose instead "an unnecessary, albeit autonomous, . . . [bad outcome or even] death."¹⁴

We do not know whether patients will so choose. Such instances need to be collected and analyzed in depth, in the same way that physicians do in situations when patients, while under the care of their physicians, inexplicably suffer from major physical morbidities or unexpectedly die.

In instances of patients' opting for an unnecessary bad outcome or death, we must find out what, if anything, went wrong. Were such decisions the result of a patient's preference that the particular attending physician or the entire medical community thought to be a wrong choice? Were such decisions due to misunderstandings about what was at stake that had not been clarified during conversations between doctors and patient? Or were such decisions the result of different

13. In the *Silent World of Doctor and Patient*, I explain:

Altruism, to the extent it exists, can only promise that doctors will try to place their patients' medical needs over their own personal needs. Even such a promise is extraordinarily difficult to fulfill in today's medical world which places such high value on economic rewards. Yet, even in the absence of any self-serving motivations altruism cannot promise that, without conversation, physicians will know what patients' needs are or that, without conversation, patients will know in what differing ways doctors can meet their needs.

KATZ, *supra* note 1, at 95.

14. Duffy, *supra* note 7, at 26.

value preferences about longevity in the face of chronic illness or different trade offs between prolongation and quality of life?

Physicians' concerns that patients may opt for a bad outcome or death also overlook that the wish to live as long and as free from suffering as possible is a compelling motivation for all human beings. While persons may engage in all kinds of ill-considered and hazardous conduct—smoking, mountain climbing—that can foreshorten life, once confronted with the choice of death or a medical intervention that will preserve life and well-being, they will, absent a severe mental disorder, choose the former except for the most compelling reasons. I doubt that physicians often will be faced with such stand offs if they learn to communicate better with their patients, take the time to dispel misunderstandings, and appreciate, in cases of disagreement, that considerable merit may reside in their patients' choice. The desire to live is very powerful, and patients will not lightly opt for death.

All that I have said so far seeks to lend additional support¹⁵ to my contention that "physicians must take the initiative and lead the way" (p. 229) in implementing the idea of mutual decisionmaking. When needy patients appear before them, physicians, by virtue of their knowledge and power, can manipulate disclosures and exploit neediness if they wish to do so¹⁶ and thus make a mockery of joint decisionmaking.

As I have suggested already, only if doctors become committed to sharing the burdens of decision can it be ascertained whether patients have the capacity for choice. My emphasis on physicians' responsibility to take the "initiative," however, could have been misunderstood.

15. These issues I discuss at length throughout *The Silent World of Doctor and Patient*. See, e.g., KATZ, *supra* note 1, Chapter IV "Sharing Authority: The Willingness to Trust," at 85-103; Chapter VI "Respecting Autonomy: The Obligation for Conversation," at 130-64; Chapter VII "Acknowledging Uncertainty: The Confrontation of Knowledge and Ignorance," at 165-206.

16. Specifically, in *The Silent World of Doctor and Patient*, I note:

[W]hat passes today for disclosure and consent in physician-patient interactions is largely an unwitting attempt by physicians to shape the disclosure process so that patients will comply with their recommendations. In a recent discussion on informed consent, a group of senior surgeons seemed genuinely puzzled by the "quaint" informed consent rule, particularly since they were certain that they could always guide patients to accept the treatment they had selected for them. "Why," they asked, "should we be forced to go through a ritual that ultimately accomplishes so little?" I responded by asking them how they would react if law at some time in the future attempted through informed consent to make patients co-decision makers? They thought that such an objective would be totally unrealistic, if not dangerous. "Patients," they asserted, "do not have the capacity to make medical decisions."

KATZ, *supra* note 1, at 26-27.

I was not trying to suggest that doctors now should take charge of decisionmaking and impose it on patients. I only wished to underscore that patients' *willingness* to make decisions and *capacity* to do so can be ascertained only once physicians are willing "to *facilitate* patients' opportunities for reflection" (p. 122) about the choices available to them. I repeatedly stated in my book that while

the posited obligation to converse introduces an element of paternalism into my prescription, [it must also be recognized that] the obligations I advocate are imposed on *both* parties; they do not ask for one party to submit to the other; they are grounded in mutuality; and they are dictated by a respect for human psychological functioning in the specific context of physician-patient decisionmaking . . . (p. 128).

In today's world, it is virtually impossible for patients to have a meaningful input on choice. The withholding and manipulation of information to ensure compliance with doctors' recommendations are too ubiquitous. If viewed from the perspective of disclosure and consent, such practices unite the medical profession in a conspiracy to exclude patients from decisionmaking. Physicians engage in this conspiracy not for nefarious reasons but out of abiding, although unexamined, convictions that unquestioned trust, obedience, and compliance are essential ingredients for good patient care.¹⁷ Patients find such convictions hard to challenge, particularly in solitary encounters with their doctors when physicians are also perceived as wishing to do good and as resenting any challenge to their goodness, even though good intentions are not what patients seek to question.

Moreover, since the medical profession has always extolled trust, obedience, and compliance as virtues and not vices, any desire on the part of patients to join in deliberations that can vitally affect patients' lives runs counter to how their own parents allowed themselves to be treated and how, in turn, the present generation of patients was socialized. They learned silent "participation" from the first time they and their parents visited their pediatricians' offices and they observed their

17. Caplan worries "that physicians . . . [may become] blinded by their anger at . . . [Katz's] suggestion that they have somehow consciously plotted against the public to maintain the norm of silence in an effort to secure wealth, prestige, and autonomy for themselves." Caplan, *supra* note 2, at 46-47. While all these considerations play a role, they are not the major reasons for the silence that pervades physician-patient relations. As I have emphasized repeatedly, doctors are deeply committed to the idea that patients' medical interests are best served if they follow doctors' orders. This unexamined conviction guides physicians' conduct, even though "there is some evidence that demonstrates that compliance and obedience are facilitated not by blind trust and obedience to authority, but rather by informed human beings who recognize each other's fallibility and limits." *Id.*

parents' deference.¹⁸ Thus, patients readily feel guilty if they wish to change practices to which they have been exposed since childhood and to which their parents had acquiesced. They may ask themselves: "Are we doing something wrong in asking for something different? Is it merely oppositional? Is it bad medicine?"

The medical profession must take the initiative and proclaim that patient participation in decisionmaking is intrinsically good and desirable. Until physicians so proclaim we cannot know whether "patients have allowed silence to substitute for conversation as a result of a conviction . . . that healing can be brought about only when the patient exemplifies the virtues of trust, obedience and compliance"¹⁹ or whether this conviction is the result of doctors' insistence that patients *surrender* themselves to trust, obedience and compliance in order to enhance the effectiveness of treatment.

The proposition that "[m]edical uncertainty and ignorance have long been seen as the primary threats to patient hope, and thus to the efficacy of medical interventions, not just by physicians but by their patients as well,"²⁰ requires careful scrutiny. I am not sure whether this perceived threat to patients' hope is not a threat to physicians' need to appear hopeful. Indeed, uncertainty and even ignorance, if frankly admitted, do not necessarily have to stifle hope. For admission of uncertainty and ignorance attests not only to the hazards of prediction (and in the absence of prediction, hope remains alive) but also to our ignorance about *vis medicatrix naturae* (the healing power of nature) (p. 196) and its contribution, often in inexplicable ways, to the prolongation of life.

18. See Katz, *Who's Afraid of Informed Consent?* 4 J. PSYCHIATRY & L. 315, 316 (1976).

Patients are afraid of informed consent because it seems to contradict their all too ready propensity for childlike surrender to the authority of experts. Patients' awe of experts has been deeply ingrained in them from the time of their first remembered visits to the pediatrician's office where they observed how easily the doctor could make obedient children out of their powerful parents.

Id.

19. Caplan notes that "[p]atients have allowed silence to substitute for conversation as a result of a conviction, *shared and reinforced by their doctors*, that healing can only be brought about when the patient exemplifies the virtues of trust, obedience and compliance." Caplan, *supra* note 2, at 45 (emphasis added). Caplan is correct that I am "less willing to grant, that it is their [the doctors'] clientele who have been equally eager to have someone occupy . . . [the] social niche . . . [of authority—once organized religion's authority declined]." *Id.* We do not know whether patients have been compelled to submit to medical authority because organized medicine provided them with no alternative but to submit, unless they wished to turn to healers who did not possess the technical training of M.D. -physicians.

20. *Id.*

Expressions of spurious hope can be self-defeating when they fly in the face of a deteriorating medical condition, and they can reinforce silence on part of the patient—born out of disbelief and unwillingness to call the physician a liar—and, in turn, on the part of the physician—born out of guilt over compounding lies with lies. We do not even know what expressions of hope patients expect from physicians. It may not be hope of cure—dying patients may have at least an intuitive appreciation of the impossibility of cure—but the hope that physicians will continue to do their level best to spare patients undue pain and discomfort; that they will stand by and not abandon patients.²¹

If, however, the answer turns out to be that patients themselves prefer silent trust, obedience, and compliance, that "patients are [indifferent] or even [hostile] to full participation in the conversations that guide medical encounters,"²² then disclosure and consent will remain an empty ritual, a charade. Far better then to dispense with disclosure and consent and reassert the authority of physicians to make decisions for patients. A half-hearted commitment to disclosure and consent will only make deception worse by giving patients, and doctors as well, the impression that a decision was made jointly when indeed it was not. It is a most grievous deception, unseemly in any interactions between human beings.

This brings me to criticisms of my work that are the result of issues that I barely considered or inadequately explored. First, I should have acknowledged more fully than I did my own dis-ease over carving out an exception to uncompromising respect for patients' choices on the ground of a serious impairment in the process of thinking about choices (pp. 156-63).²³ It is a narrow exception, for

I would [only] consider disobeying a patient's choice when two conditions have been met: One, the consequences of non-intervention pose *grave risks* to a patient's *immediate physical condition* and, two, *the process of thinking about choices is so seriously impaired* that neither physician nor patient seem to know what one or both wish

21. I suggest in *The Silent World of Doctor and Patient* that:

[P]atients hope that physicians can be trusted to observe carefully, to treat them with care, to alleviate unnecessary suffering, to discuss with them the implications of uncertainty's inevitable presence, to give the unpredictable forces of nature a helping hand, and, above all, to remain honestly present and not abandon patients when they need them most.

KATZ, *supra* note 1, at 194. See also KATZ, *supra* note 1, Chapter VIII "The Abandonment of Patients: A Final Argument Against Silence," at 207-29.

22. Caplan, *supra* note 2, at 45.

23. The entire article by Baron is devoted to a perceptive reanalysis of this exception, also in the context of my imaginary conversation with Mr. D. See Baron, *supra* note 2.

to convey to the other. With respect to the first condition, I would limit interferences with patients' choices to illnesses for which available diagnostic and therapeutic interventions have a reasonable chance of preventing *death or predictable, serious, and irreversible physical injuries* in instances when death or injury would occur *within a relatively short period of time*. (The emphasis on serious physical consequences seeks to balance the values of respect for self-determination and well-being. The emphasis on the time factor seeks to acknowledge that it can take time to clarify confusion and misconceptions. For example, time may not be available when, without intervention, death or injury are imminent.) The first condition, however, is only a *necessary* one for intervention, it is *not decisive* by itself. Interference with patients' choices must also meet another test: The process of thinking about choices must be seriously impaired (pp. 157-58).²⁴

I was tempted to omit this section but ultimately I was unwilling to do so, even though I knew that the exception would invite criticism and could easily be construed as giving physicians greater license than I had intended.

My exception is not a retreat to paternalism but a recognition of the fact that any good principle that defines human conduct can never rule absolute. Of course, the danger exists, as is true for any departure from principle, that if license is taken it will be expanded beyond its rightful limits. The temptation needs to be resisted by the most careful review of cases in which the exception has been applied.

On further reflection, criticism of my bow to paternalism notwithstanding, I still believe that the exception must stand for one major reason:

[T]he right to self-determination about ultimate choices cannot be properly exercised without first attending to the processes of self-reflection and reflection with others. This holds true for patients as well as for physicians. Contrary views have paid insufficient respect not only to human proclivities for unconscious and irrational decision making but also, and more importantly, to the possibilities of bringing some of these determinants to greater awareness. Such views on autonomy and self-determination do not pay respect to "self-defined" individuals; instead, such views inhibit opportunities for women and men to become clearer about how they may wish to define themselves, abandoning them instead to a malignant fate. In the context of physician-patient decision making, it must be recognized that illness—including the fears and hopes it engenders, the

24. (emphasis added).

ignorance in which it is embedded, the realistic and unrealistic expectations it mobilizes—can contribute to tilting the balance in patients and physicians further toward irrationality and choices that, on reflection, both might wish to reconsider. In short, I seek to justify the duty to reflection on the grounds of human beings' capacities to take their unconscious and irrationality more fully into account (p. 124).

In moments of crisis, when little time is available before serious irreversible harm is likely to occur and when neither physician nor patient seems to know what one or both wish to convey to the other, I would overrule patients' choices. The reason is that I have no idea, as in the case of Mr. D., whether acquiescing to his refusal to talk with me constitutes respect for his autonomy in the sense in which I define it.

However, despite the need for the exception, I must have been uneasy when I put it on paper. Otherwise, I would have been less "impersonal, unemotional and deontological"²⁵ in the way in which I phrased my imaginary dialogue with Mr. D.²⁶ I might then have been more forthright about my feelings of impotence in the face of his refusal to talk. I might have considered telling him: "Try to see things my way; [w]ould you be willing to . . . [talk to me], [p]lease!"²⁷ These are good suggestions, but what if the patient had persisted in his refusal, what then? Should I not have intervened? I could not have stood by and let him die.

Thus, I admit to my dis-ease over the exception, yet I cannot eliminate it. Paternalism cannot be banished completely. It is a paternalism, however, not based on notions of mental health or illness,²⁸ but on basic assumptions about the psychological nature of human

25. Baron, *supra* note 2, at 38.

26. Baron cites in considerable detail my imaginary conversation with Mr. D. *Id.* at 37-38.

27. *Id.* at 38.

28. I did not wish to suggest that physicians might now "force such treatment on patients where *mental* health demanded it." *Id.* at 33. In his book, *LEGAL FRONTIERS OF DEATH AND DYING*, Norman Cantor states:

Professor Jay Katz, a staunch advocate of informed consent, suggests an interesting limitation on a patient's prerogative to decline life-saving medical treatment. He contends that a competent patient ought to be entitled to reject such treatment even for a "foolish" or "unwise" reason—so long as the patient articulates *some* reason for his decision. If the patient insists on rejecting life-saving treatment "without any explanation," Professor Katz would be inclined to override the patient's determination.

The motivation behind the Katz position is certainly commendable. It is aimed at assuring that the patient's decision is a truly informed one. The physician seeks to know what motivates the patient to make a seemingly unreasoned decision, in order to at least try and confront the patient's objections to treatment.

beings. These assumptions led me to make distinctions between thinking about choices and choice itself²⁹ as well as to allow for the rare exception of overruling choice when *reflection about choice* is impaired. Paradoxical as it may sound, I did so because of the high value I place on autonomy, an autonomy that is not defined solely by a “no” or “yes” response.³⁰

There can be no quarrel with the effort to engage the patient in careful conversation about his life-rejecting determination. The question is, what follows if the patient persists in his refusal to explain his decision. My own preference would be to respect the patient's refusal so long as a conscientious determination can be made—based on the patient's general demeanor and the other conversations — *that the patient is competent*. This would be so even in the rare instance when the patient chooses to cloud his ultimate motivations in silence.

N. CANTOR, LEGAL FRONTIERS OF DEATH AND DYING 25 (1987) (emphasis added). Cantor suggests that the decision whether to respect a patient's choice ultimately should also depend on an evaluation of his or her competence. *But see Katz, Can Principles Survive in Situations of Critical Care?* in ETHICS AND CRITICAL CARE 4-67 (J. C. Moskop & L. Kopelman eds. 1985).

[U]nilateral assessments [of competence by psychiatric consultants] that implicitly, if not explicitly, stress the patient's irrationality and not the physician's can readily compromise *mutual* exploration from its very beginning. They tend to fuel a patient's resentment over not being taken seriously, over having to establish his credentials as a competent person, however much unintended by the physician Required instead is a bilateral conversation between doctor and patient that explores *their* expectations of one another, that identifies *their* misconceptions, *their* confusions and, most importantly, that seeks to clarify why *they* wish different things from one another. All this must be done in the spirit not of assessing, evaluating, or judging anything but of better understanding one another.

Id. at 51-52.

29. Self-determination contains . . . two intertwined, though separable ideas. One looks at conduct in relation to the external world, at conduct in relation to action. I call this external component of self-determination *choice*. It has also been spoken of as freedom of action. The other looks at conduct in relation to the internal world, at conduct in relation to thinking about choices by oneself and with others prior to action. I call this internal component of self-determination *reflection or thinking about choices*. Traditionally, discussions of self-determination have emphasized the external component. I shall argue instead that both the external and internal components deserve equal and separate consideration.

KATZ, *supra* note 1, at 110-11.

30. [T]he requirement for conversation creates inevitable conflicts with the right to privacy—the right to keep one's thoughts and feelings to oneself. Thus, the imposition of an obligation to converse is disrespectful of the right to have one's initial choice, including the right not to converse, honored. Refusals to converse, however, totally obscure both patients' and doctors' understanding of how they arrived at their decision. This is particularly true when patients either decline a needed medical intervention or accept it unquestioningly. Respect for psychological autonomy becomes severely compromised when refusals or acceptances are heeded without question. Here the principle of privacy must bend to psychological autonomy. (This may turn out to be a rare Hobson's choice, for I expect that most patients, if invited by their physicians, will welcome conversation.)

KATZ, *supra* note 1, at 127-28.

Second, I should have written more on the role of patients' family members in the decisionmaking process.³¹ Particularly when patients and physicians disagree, family members' assistance in clarifying matters should, of course, be invited. Family members can perform the important function of explaining to their loved ones what is at stake. Since they know the patient more intimately, they may perform this task more easily than the physician. They perhaps can find the words to make the patient understand.³²

Family members, ministers, priests, rabbis, social workers, nurses, and friends have important roles to play in the process of reflecting about choices but they cannot, they must not, be allowed to veto the patient's decision.³³ The ultimate choice belongs to the patient, not only on the grounds of self-determination and autonomy, although that alone is sufficient, but also on the ground that patients' and their families' interests do not necessarily coincide, just as physicians' and patients' interests are not necessarily identical. This holds true whether the families' decision is for or against treatment.

Third, I also did not explore the question whether disclosure and consent should rule absolute in all doctor-patient interactions. Perhaps, at this early stage in the life of informed consent, imposition of such an absolute rule is asking far too much. Indeed, for some time I have wondered whether one unitary informed consent doctrine can ever serve well all situations encompassed by the practice of medicine. It may make sense to develop a variety of informed consent doctrines for various well-defined subgroups of medical practice. Let me briefly describe four such possible subgroups:

(1) For relatively minor, time-limited disorders for which treatments are available that do not expose patients to undue risks, *e.g.*, the common cold, non-specific headaches, or certain dermatological disorders, informed consent, for the time being, could be dispensed with altogether.³⁴

31. Arthur Dyck correctly points to this omission and makes many perceptive comments about the "network of relations" that can assist patients in achieving "an unimpaired process of thinking about choices." Dyck, *Self-Determination and Moral Responsibility*, 9 W. NEW ENG. L. REV. 53, 58 (1987).

32. Dyck gives a number of examples that demonstrate the contributions family members can make to the process of thinking about choices. In two instances these contributions led the patients to reconsider decision against treatment. *Id.* at 58-59.

33. *But see id.* at 59. Dyck also states, "Moral responsibility may sometimes, however, demand that physicians and family members oppose a choice even though the process of making the choice does not seem impaired." *Id.*

34. Note the qualifying phrase "for the time being." Eventually this sub-group should also be covered by its own rule of informed consent. I only suggest that informed

(2) For acute disorders, *e.g.*, myocardial infarctions that require immediate intervention as well as keeping the patient as anxiety-free as possible, the informed consent process may have to be curtailed. Joint decisionmaking may have to be limited to a few essential matters about diagnosis and treatment.

(3) For elective procedures, *e.g.*, hysterectomies, tonsillectomies, and cholecystectomies, or procedures for which a variety of treatment (and no treatment) options are available and there is no rush to proceed, joint decisionmaking should become an absolute rule, unless patients opt for delegating decisionmaking to their physicians.

However, prior to accepting this responsibility physicians should make reasonable inquiries in order to determine whether responsibility is delegated out of fear of offending them, concern about imposing on their time, or patients' lack of knowledge necessary to ask the questions that need to be asked. Patients must be reassured that doctors are willing to take the time to talk, and that doctors are prepared to provide the necessary background information so that patients can ask appropriate questions. In elective procedures informed consent is a *sine que non*. Disclosure and consent will lead to fewer interventions and contribute to reducing the staggering cost of health care.

(4) For conditions, *e.g.*, cancers, in which prognosis is dire and fatal outcome a likely prospect, the extent of physicians' disclosure and obtaining patients' consent may be ascertainable only after physicians have probed patients' reactions to knowing fully the implications of their disease on life expectancy. Physicians should be guided by the strongest presumption in favor of disclosure and consent, which can be modified only by clear and carefully documented evidence that patients do not wish to be fully informed.

While in recent decades physicians increasingly have revealed the diagnosis of malignancy to patients, little has changed with respect to discussing with patients therapeutic options and prognosis. In light of the spectacular advances in the treatment of cancer, for example, disclosure of diagnosis has become inevitable so that physicians can employ the treatment modalities now available to patients. At the same time, the risks and benefits of these therapies—their impact on quality of life, their often experimental nature, or the fact that choices can be made among many alternatives, including the alternative of no treat-

consent be dispensed with for the time being, to highlight (1) the greater importance of developing informed consent doctrines for the other three groups; and (2) the crucial importance of physicians acknowledging that no informed consent is sought or being obtained, and not giving the appearance that disclosures are made and consent is being obtained when this is not the case.

ment—are still all too rarely explored with patients and subjected to joint decisionmaking.

Thus, non-disclosure has merely shifted from diagnosis to therapy and prognosis. Whatever the merits of deeply held convictions that hope must be maintained for patients' benefit and that patients do not wish to be informed about their dire circumstances, it is equally clear that physicians have given insufficient attention to the possibility that many, or at least a significant number of patients, prefer to know what is in store for them.

Nor do we know whether physicians' acknowledgment of the sad fact that only a "scant menu of options,"³⁵ are available, *i.e.*, "choices about slow and rapid death, painful and less painful death,"³⁶ will be preferred by patients, rather than the withholding of such information. Patients may know more about their conditions than physicians appreciate and resent that they have been silently condemned to end life in pain and without any control over how to live their lives during their last months in this world. We do not know how patients feel because physicians have not tried to consult them. Once departed, patients' feelings are buried with their corpses.

Moreover, we know all too little about dying patients' capacities to deny, repress, and engage in magical thinking about their illnesses, if they wish to defend themselves against a full realization of their hopeless conditions. Those who are so inclined will resort to these adaptive and defensive mechanisms without being aided and abetted by their doctors. If physicians desist from shielding patients from the truth, it will become possible to distinguish better between patients who wish to employ their own defensive maneuvers and those who prefer to prepare for death with greater awareness.

* * * *

Matthew Arnold concluded his poem *Dover Beach* with these optimistic-pessimistic words:

Ah, love, let us be true
To one another! for the world, which seems
To lie before us like a land of dreams,
So various, so beautiful, so new,
Hath really neither joy, nor love, nor light,
Nor certitude, nor peace, nor help for pain;
And we are here as on a darkling plain

35. Caplan, *supra* note 2, at 50.

36. *Id.*

Swept with confused alarms of struggle and flight,
Where ignorant armies clash by night.³⁷

These are apt sentiments for what I have tried to explore in my inquiries on informed consent and physician-patient decisionmaking. In today's world, conversations between physicians and patients about medical choices are still conducted "on a darkling plain . . . with confused alarms of struggle and flight."

I accept as a correct appreciation of my position the criticism that chides me for depicting physicians and patients too much as adversaries³⁸ and not as persons united in a common cause. In the current climate of medical decisionmaking, I indeed view physicians and patients as adversaries. But I also have been misunderstood about my depiction. I did not wish to imply that doctors, in their physical ministrations, are not deeply committed to doing their level best for their patients according to their best professional judgment. In that sense doctors are patients' friends and not their adversaries.

Yet, it is according to *doctors'* best judgments that patients are cared for, and not necessarily according to their *patients'* best judgment. The two *may* or *may not* coincide. Paradoxical as it may sound, it is precisely because of the tremendous advances in medical science during the last fifty years that physicians' objectives and those of patients have diverged more than was true in earlier times. As I have repeatedly emphasized, choice among a variety of medical options has become an integral part of the practice of modern medicine. Risks of treatment accompany benefits, and iatrogenic complications have also become an integral aspect of the practice of modern medicine. Quality of life problems have multiplied as physicians have developed techniques for keeping patients alive for longer and longer periods of time.

With choice such a new development, a silent world of doctor and patient which precludes patient input into choices that can affect their physical and psychological well-being in decisive ways makes adversaries out of them, because the treatment selected by the physicians may not comport with the patients' choice of treatment. Thus, doctor and patient can become engaged "in a struggle and flight," as Matthew Arnold so vividly depicts in a different context, where parties "ignorant" of their respective wishes can only "clash by night."

The poet, in part, despaired: "The world . . . so beautiful . . . hath

37. Arnold, "Dover Beach," in *THE POETICAL WORKS OF MATTHEW ARNOLD* 210 (C. B. Tinker & H. F. Lowry eds. 1957).

38. Duffy, *supra* note 7, at 24-25.

really neither joy, nor love . . . nor certitude, nor help for pain” Yet, he began on an optimistic note, “[a]h, love let us be true to one another” In these stanzas, he may have wished to hold out the hope that if two persons can learn to be true to one another, the world may yet become filled with joy and help for pain.

In reflecting on this poem, I was reminded of the two cornerstones of Greek medicine: *philanthropia* (love of man) and *philotechnia* (love of the art [of healing]).³⁹ Such love requires trust. Yet, can trust flourish unless doctor and patient are true to one another? Should it not be a trust based on truth and mutual assent rather than on obedience and compliance—the kind of trust that underlies the idea of informed consent? Cannot such a trust be realized only if physicians cease to control their patients and, instead, learn to trust their patients as doctors wish to be trusted by their patients? Is not the true meaning of trust the capacity to trust oneself *and* the other?

If the idea of informed consent were to govern physician-patient relations, physicians’ moral authority would be based not only upon their expert knowledge to diagnose and treat but also upon an awareness of the tragic limitations of their expert knowledge.⁴⁰ They would then be forced to reflect more deeply on their moral responsibility to share with or withhold from patients both their knowledge and ignorance. Patients’ moral authority would rest on their right to care for their bodies in their own ways, including delegation of that authority to their doctors.

Fidelity to the idea of informed consent eschews physicians’ unilateral exercise of moral authority and shifts the focus to new questions: must not physicians, in light of their knowledge and ignorance, impress on patients that medical decisions are best made jointly? Must not patients learn that the moral authority to make choices belongs to them and not to their physicians?

The contributors to this volume have wrestled hard with the problems of trust and mutuality between doctors and patients. If the

39. P. ENTRALGO, DOCTOR AND PATIENT 45-51 (F. Partridge trans. 1969).

40. As I state in *The Silent World of Doctor and Patient*:

[T]o trust patients, physicians first must learn to trust themselves 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 at others — to devote themselves fully to their patients’ needs. They must also learn not to be unduly embarrassed by their personal and professional ignorance and to trust their patients to react appropriately to such acknowledgments.

KATZ, *supra* note 1, at 102-03.

authors' insights and recommendations⁴¹ will be subjected to further, relentless scrutiny, we may yet see the dawn of a new age in which physicians and patients will not encounter each other on "a darkling plain."

41. I cannot conclude without apologizing for not commenting on all the articles that are part of this symposium. I of course was gratified that Professor Annas, Professor Johnson, Professor Miller, Judge Dunphy and Mr. Cross, and Professor Rhoden found my book useful in pursuit of their specific research interests; that Chief Justice Doolin incorporated my views in *Scott v. Bradford*; and that Professor Minow extended my observations to broader areas of human interaction. I can only acknowledge that I learned much from them, but to do justice to their contributions would have required writing another book.