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ON KNOWING ONE'S CHAINS AND DECKING THEM WITH FLOWERS: LIMITS ON PATIENT AUTONOMY IN "THE SILENT WORLD OF DOCTOR AND PATIENT"

CHARLES H. BARON*

In Chapter VI of *The Silent World of Doctor and Patient*,¹ Jay Katz admits to the reader that, despite his very strong belief in patient autonomy, even he reaches a point where he would feel entitled to overrule a patient's decision to refuse treatment: "Despite all that I have said so far, rare situations may arise when patients' choices should not be honored" (p. 156). As an example, he offers the case of Mr. D., "a previously healthy 66-year-old black man who had come to the emergency room [of Dr. Mark Siegler] suffering from an acute febrile illness of three days' duration"² (p. 156). Although Mr. D. consented to hospitalization, X-rays, and antibiotics for what appeared to be a critical illness, he refused two diagnostic procedures—a bronchial brushing to obtain lung tissue and a bone marrow examination—which were uncomfortable but routine and "medically necessary" for his proper treatment. When his physicians repeatedly attempted to explain the necessity for these procedures, Mr. D. became angry and began to refuse even routine blood tests and X-rays. A day later, Mr. D. appeared to be near death. He then refused to be placed on a respirator. A psychiatric consultant had interviewed Mr. D. and concluded "that Mr. D. understood the severity of his illness . . . and that he was making a rational choice in refusing the tests" (p. 156). Dr. Siegler himself had conducted two forty-five minute interviews with the patient and had concluded that Mr. D.

understood the gravity of his situation. For example, when I told him he was dying, he replied: "Everyone has to die. If I die now, I

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

2. See also Siegler, *Critical Illness: The Limits of Autonomy*, HASTINGS CENTER REP., Oct. 1977, at 12.

am ready." When I asked him if he came to the hospital to be helped, he stated: "I want to be helped. I want you to treat me with whatever medicine you think I need. I don't want any more tests and I don't want the breathing machine."

I gradually became convinced that despite the severity of his illness and his high fever, he was making a conscious, rational decision to selectively refuse a particular kind of treatment (p. 156).

On the basis of these determinations regarding competency, Dr. Siegler decided to respect Mr. D.'s objections and allow him to die.

Professor Katz recognizes that Dr. Siegler based this decision upon a "belief in the rights of individuals to determine their own destinies" much like his own. "Yet," he concludes, "I might not have deferred to Mr. D.'s wishes, if he had without any explanation persisted in his refusal to undergo diagnostic tests" (p. 157). "Had Mr. D. been unwilling to give me his reasons for the refusal, I might have gone forward with the diagnostic tests" (p. 157). Professor Katz recognizes as well that some may view his position as surprising in light of the strong defense of patient autonomy which is the burden of every other portion of his book. Thus he admits to an obligation to "both define the conditions in which a physician ought to consider taking such action and justify such exceptions to the rule of respecting patients' choices" (p. 157). He immediately goes on to perform the first task in a simple and direct fashion. However, his effort to deal with the second not only seems to fail in its narrow goal but reveals problems in the central thesis of the book.

Under what conditions would he consider disobeying a patient's choice? Only when the situation meets two conditions: "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 to convey to the other" (pp. 156-57). Of course, the first condition sounds very much like the traditional basis for forcing treatment employed by the physicians whom Professor Katz criticizes. Thus, his emphasis is on the second condition. "The first condition . . . is only a *necessary* one for the 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" (p. 158). But what exactly does Professor Katz mean by such "serious impairment" and why does such impairment justify overruling patient choices? Without clear answers to these questions one might be left with the uneasy feeling that Professor Katz has offered us psychiatric paternalism as a replacement for medical paternal-

ism. Although physicians could no longer force treatment on patients on the ground that *physical* health demands it, they might force such treatment on patients where *mental* health demanded it. This might still represent a net gain for advocates of patient autonomy,³ in that the new paternalism would justify fewer interventions than the old—at least in theory. But why should “psychiatric necessity” have any greater power to override patient objections than “medical necessity?”

I believe that the book does provide a basis for a good answer as to why impairment of the process of discussion with patients about their choices might justify intervention by doctors. However, although this answer is based upon Professor Katz’s insights, it differs in significant respects from any version of a justification which Professor Katz provides in his book. As I will attempt to show, Professor Katz’s arguments fail to the extent that they preserve, in this portion of the book, medical traditions of pretense to omnipotence which he eschews at almost every other point in it. The author takes us only part of the way to enlightenment when he urges doctors to be honest with themselves and their patients about the uncertainties of medicine and their own professional limitations. What he misses is the occasional need for doctors to be honest about their personal limitations, their human weaknesses and needs. Professor Katz’s arguments for forced intervention can hope to succeed, I contend, only after they are translated into terms which draw on this honest recognition of the humanity of physicians. However, as I will attempt to show, to the extent that this honest recognition of physician need is shared with patients, the very act of communicating the need is likely to make unnecessary the forced intervention which the need communicated otherwise would be used to justify.

At the beginning of the last paragraph on page 158, after introducing his conditions for intervention, Professor Katz states: “Before trying to justify why the overruling of patients’ choices should be given serious consideration if these two conditions prevail, I want to say more about Mr. D.” Four pages later, at the beginning of the last paragraph on page 162, he says: “I appreciate the problem of occasional coercion that my prescription raises. While no principle can rule absolute, including the principle of freedom of choice, exceptions to it must be most narrowly circumscribed and justified. Let me add

3. For my own position strongly in favor of patient autonomy, see Baron, *Licensure of Health Care Professionals: The Consumer’s Case for Abolition*, 9 AM. J.L. & MED. 335 (1983); Baron, *Medical Paternalism and the Rule of Law: A Reply to Dr. Relman*, 4 AM. J.L. & MED. 337 (1979).

to *what I have already said* about justifications.”⁴ Clearly, we are being told to look in those four intervening pages for important statements as to what justifies narrowly circumscribed intervention. But, as it turns out, what is there will yield only to the reader who is willing to work hard to find it.

In great part, the four pages are taken up with the discussion of three cases: Mr. D.’s, a second case involving a fifty-seven year old woman who would not consent to a hysterectomy because she refused to believe that she had cancer, and a third involving a fifteen year old girl who refused high risk heart surgery on the ground that, despite doctors’ assurances to the contrary, she would suffer “intolerable” post-operative pain. In the two latter cases, doctors ultimately were able to obtain consent from the patients by eliciting their hidden concerns and allaying them. Continued conversation elicited from the fifty-seven year old woman the fact that prejudice prevented her from accepting the dire cancer diagnosis from her treating physician because he was black. Discussions with a white doctor and the patient’s daughter led her to drop her objections to surgery. “Without sustained conversation her reasons for the initial refusal of a hysterectomy might never have been clarified and condemned her to an unnecessary death” (p. 161). Continued conversation also led the fifteen year old to opt for her operation and resulted in a happy ending. Consulted by her physicians, Professor Katz had been moved to suggest that a psychiatric social worker talk to the patient in an attempt to “clarify the confusion between childhood memories and current realities” (p. 162).

I was able to throw some light on the mystery of her concern over pain and suffering. As I listened to her doctors, I recalled painful memories, reported by patients in psychoanalytic treatment, about childhood operations. These stories depicted the sudden shift from happy childhood memories to painful ones about hospitals and operations, memories of physical discomfort that were augmented by psychic suffering and confusion over what my patients had perceived as a “betrayal” by previously caring parents who, they felt, had cruelly turned against them. I wondered whether such excruciatingly painful, unconscious memories might not have influenced her decision (pp. 161-62).

Again, continuing conversation had done the trick. In the instance of the fifteen year old, “the availability of a person who could draw on his professional experiences made the resolution of a puzzling problem

4. (emphasis added).

easier. Yet, even if I had not been there, a commitment to conversation might have brought about the same result" (p. 162).

In the case of Mr. D., Professor Katz can only imagine what difference continuing conversation might have made. Perhaps Mr. D. believed the proposed diagnostic tests to be experimental rather than a diagnostic necessity. This belief might have been a result of the fact that he knew himself to be at a teaching hospital. In fact, Dr. Siegler found out only after Mr. D.'s death that he had, ten years earlier, signed himself out of a hospital after refusing a bone marrow examination.

Since in the intervening years he had not been any worse off for his refusal, he might have wondered whether this test was not equally unnecessary now. Had he told me about this experience, perhaps I could have impressed on him that the two situations were not necessarily comparable. From there, we could have gone on to talk about his mistrust of doctors and the uncertainties of medicine. Who knows what else we might then have explored (pp. 159-60).

It is easy to be swept along by Professor Katz's description of a world in which everyone gains by the doctor's intervention. In two cases, a commitment to conversation led to what appeared to be informed consent to "medically necessary" procedures. In a third, it might have led to such consent if it had been pursued. Does Professor Katz think that that fact gave him the right to force such conversation on Mr. D. if he had refused it? Apparently he does. Of Mr. D.'s case he says:

If on the basis of my nagging and unanswered questions I had intervened, I would not have done so because I thought his decision unwise, foolish or whatever, but because I had no idea whatever why he had decided what he did. I would have felt confused and been uncertain whether he was confused as well (p. 160).

And at the conclusion of his discussion of the two other cases he states: "Both stories, I believe, reinforce the lessons to be learned from Mr. D.'s case: the obligation to converse so that misconceptions, confusion, fears, and ignorance can be clarified; and the necessity not to accept prematurely patients' refusal to engage in such conversations" (p. 162). If we leave the justification for intervention at this, then he has surely replaced medical paternalism with psychiatric paternalism. Conversing about reasons for refusing treatment is necessary for the patient's mental health; thus the doctor and patient are obligated to converse whether or not the patient wants it.

Happily, however, Professor Katz's justification for intervention

need not be left at this. Other observations which he makes—almost in passing at times—provide a basis for a slightly altered form of intervention; one which might well furnish him with everything he wants in a fashion more consistent with all of the valuable things in the rest of this excellent book. At the point on page 162 where he speaks of adding “to what I have already said about justifications,” he goes on to say:

Respect for patients' vulnerability to ill-considered thoughts and actions requires that they engage in conversation. *Physicians however, also have needs that deserve respect.* In situations like Mr. D.'s, their strong ethical commitment to caring for patients can impose intolerable burdens on them. In these instances, doctors may never know whether they have explained themselves satisfactorily to their patients. Doctors may then doubt whether they have taken the necessary time or made the necessary effort to make themselves understood. Such doubts can lead to nagging guilt feelings over having failed in one's professional obligations. *Assuaging guilt-inducing doubts that may haunt physicians for a lifetime is another reason for my insistence on conversation* (pp. 162-63).⁵

The theme of the needs of physicians as a basis for justifying their intervention in patient decisionmaking surfaces at other places in the book. For example, Professor Katz states in Chapter V that:

[R]espect for the great importance physicians place on beneficence and loyalty to their patients may suggest that physicians have a right and need to be informed why their patients do not choose to follow a proposed course of action so that doctors can be reasonably certain that their patients have understood their recommendations (p. 112).

The “needs of physicians” basis for intervention explains much that would otherwise seem inexplicable in the book. For example, in his discussion of Mr. D.'s case, Professor Katz asks “What could Mr. D. have told me that would have led me to bow to his decision?” He then answers: “It is easy to answer this question at the other end of the continuum from patients' silence to communication. For example, if Mr. D. had been a Jehovah's Witness and refused tests on religious grounds, I would have still talked to him but readily accepted his decision” (p. 160). Why should such grounds be so readily accepted and others not be? It would seem to be because they “assuage the guilt-inducing doubts” there might otherwise be that the patient is refusing treatment because the doctor has failed somehow in his or her role.

5. (emphasis added).

The patient is refusing treatment for reasons beyond the control of the doctor—the patient’s indoctrination by the church—and not because “we had not been able to clarify misconceptions, distortions and ignorance, and that I had not been able to impress on him that he mattered and was worthy of my time and effort” (p. 160).

But if it is the needs of physicians which, in the end, justify Professor Katz’s intervention in a treatment refusal decision, why does he not feel that physicians should make that clear to the patient? At one point, Professor Katz gives us an example of the kind of conversation he would like to have been able to conduct with Mr. D. in an effort to have him share his reasons for refusing treatment.

Had I encountered Mr. D., I would have told him that I was puzzled by his refusal to undergo the proposed diagnostic tests. I would have expressed to him my concern and confusion over my lack of understanding of what had led him to his decision, as well as my concern and fear of perhaps not having adequately conveyed to him why I thought that these tests were so essential to his well-being.

I would have impressed on him the necessity of our talking together. Indeed, I would have insisted on our talking together as long as time permitted in order to clarify our respective positions. I would have promised him that I had every intention of ultimately respecting his wishes, but that I could not make an absolute promise to do so, for it could turn out that the acuteness and seriousness of his condition might require an intervention prior to our having made ourselves understood to one another. I would have added that I expected this to be an unlikely outcome, but that it could happen. Throughout, I would have tried to convey to Mr. D. that my insistence on conversation was based on two concepts: to make sure that I had cleared up any of his misconceptions and confusion about the need for the diagnostic tests, and that he understood why I considered the performance of these tests so essential.

If in the midst of our talking together, Mr. D. had “turned away,” and bid me to “leave [him] alone,” I would not have left his bedside. . . . I would have felt impotent and experienced Mr. D. as all powerful. And I would have recalled what Burt had written in *Taking Care of Strangers*⁶ that such depictions of myself and him might have enraged me and made me turn away out of an unconscious wish to hurt him. At the same time, I might have overlooked that the patient too, appearances notwithstanding, was struggling with feelings of impotence out of “the intense stress [he was suffer-

6. R. BURT, *TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS* (1979).

ing] from the incapacitating experience of his illness.” Thus, I would have stayed with him and renewed my invitation to talk with one another. Had he continued to decline the invitation, I would eventually have been forced to tell him that I might very well order the tests, place him on a respirator, and resuscitate him if he refused to talk with me. “There is too much that we both do not understand,” I would have added, “and you must not hide behind silence” (pp.158-59).

Although there is, at the outset, some mention of the physicians’ fear that they might have failed to convey adequately the facts to their patients, the discussion quickly becomes impersonal, unemotional, and deontological in tone. At times Professor Katz makes it appear that some impersonal force of reason has taken over the relationship. “Necessity” dictates that doctor and patient talk together. The “acuteness and seriousness of the patients’ condition might *require*” an intervention. The physician might be “forced” to order the tests and the use of a respirator to resuscitate the patient. The patient “must not” hide behind silence. At other times the physician admits to responsibility as an active participant in the events, but in a fashion which announces that the physician ultimately controls the relationship. The doctor “insists” that they talk together and decides whether their conversation is up to standard. If it is not, the doctor gets to order the tests. Is this the way that two autonomous human beings are to carry on a conversation? Where are “Try to see things my way,” “Would you be willing to do this for me?” and “Please!”? To what extent is the patient made to feel autonomous? In one version of the presentation, the patient is made to feel that both doctor and patient are at the mercy of the dictates of reason. In the other, the patient is made to feel ultimately at the mercy of the doctor. Is this more or less likely to make the patient feel like conversing?

At the conclusion of the section on “Overruling Patients’ Choices,” Professor Katz suggests that doctors would rarely be faced with the necessity for overruling such choices if the medical profession took seriously the need for “conversation in preparation for choice.”

Patients would soon learn from their doctors’ example that decision making in medicine can rarely be carried out in isolation, but only through mutual interaction. Thomas Aquinas appreciated this when he spoke of the need for “fraternal correction.” Or as Paul Tillich once put it, “humanity is attained by self-determination and by other-determination in mutual dependence.” Such insights will eventually make my limited exception to patient choice a relic of the past. Patients will learn to be less afraid to voice their reasons for

refusal because they will be confident that such disclosures will only invite "fraternal correction" through conversation, but no more than that (p. 163).⁷

But the sort of doctor-patient conversation which Professor Katz offers us does not seem one of "mutual dependence" which risks only "fraternal correction." It is one in which the patient is made to feel that the doctor carries the ultimate authority. The doctor has merely conceded to the patient some portion of the decisionmaking authority subject to the condition that the patient pass some test by giving the "right" answers concerning the reasons for refusing treatment. As with Burt's doctor, why wouldn't such a situation of impotence be most likely to enrage the patient and cause him or her to turn away out of a desire to hurt the physician?

To make the needed correction here, we need only take Professor Katz's principles of doctor-patient conversation a step further. Throughout his book he has called upon doctors to be more honest with themselves and their patients about the uncertainties of medicine and their own professional limitations. Professor Katz has said that:

[P]hysicians must first 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 (pp. 102-03).

What is needed now is to extend these insights to the level of the doctors' feelings of neediness and weakness in the doctor-patient relationship. Doctors need to acknowledge to themselves and their patients that it is out of their need and weakness that they are asking the patient to engage in conversation regarding the reasons for refusing treatment. Although the doctor can, of course, attempt to force a discussion through the threat of coerced treatment, the resulting dialogue is unlikely to be the kind of true conversation that Professor Katz would like. Much better—and much more likely to be effective—would be for doctors to make clear that they are asking the patient for a *favor*. The doctors should share with the patient that it is the *doctors* who are made to feel impotent by the patient's refusal to talk and that they view the patient as "all-powerful" as a result. Doctors should

7. (citations omitted).

make clear that what they need is to be reassured by their patients that the patient's refusal to accept treatment is not the result of some failing in the doctor's handling of the case and its presentation. Patients thus realize that they are no longer impotent subjects being put through some test by those in authority before they can get what they want. Rather, one human being is asking another human being to do the first human being a favor. It is a favor which costs the patient very little. And it is a favor which clearly means a great deal to the doctor—someone who has done a great many favors for the patient in the past and stands ready to do more in the future. Is it likely that any patient would refuse such a request?

At one point in the book, Professor Katz urges upon his doctor-readers⁸ an effort to disabuse their patients of irrational and unconscious expectations that the doctor will play the role of parent with them. At the same time, he cautions them not to expect instant success in that effort:

Such efforts will not always meet with success and, indeed, can never be totally successful. However hard one tries to be true to Rousseau's aphorism that 'It is better to know one's chains than to deck them with flowers,' some chains that imprison the human mind inevitably remain decked with flowers (p. 147).

Of course, Professor Katz does not need to be convinced that there is

8. That Professor Katz has so obviously written the book for the doctor-reader raises a problem which is related to the theme of this essay. It is a further betrayal of vestiges of paternalism within Professor Katz that he believes that ultimate responsibility for developing meaningful conversation with the patient resides with the doctor. In the book's closing pages, Professor Katz states: "*Both* physicians and patients must rethink basic assumptions about their relationship and about mutual decisionmaking. Physicians here must take the initiative and lead the way." KATZ, *supra* note 1, at 229. Not surprisingly, this attitude becomes even more manifest when he sees aspects of his own medical specialty implicated in the effort. "A greater awareness by both parties of the power of transference and the obligation . . . must be assumed by professionals rather than by their patients. Patients can only learn of the power of transference over time *and through personal experiences with aware physicians who educate them about its manifestations.*" KATZ, *supra* note 1, at 144-45 (emphasis supplied). Are patients really so childlike and incompetent that they are incapable of learning for themselves and from each other of the tendency toward and dangers of the parent/child relationship in medicine? If evidence that they are not were needed, the experience of the People's Medical Society would seem to be one source for supplying it.

Professor Katz could have written the book for patients, calling upon them to act in a more adult fashion with their doctors and to pressure their doctors to be more adult and less parental. Or he could have called upon both doctor and patient to exhibit and request more adult behavior. The fact that Professor Katz addressed the book to doctors and recognizes them as ultimately responsible for making informed consent work subtly reinforces the very dependency of the patient which Professor Katz otherwise seeks to eliminate.

at least as much difficulty in getting doctors to know the chains that imprison their minds. Doctors are at least as interested in seeing their patients as needy and grateful children as patients are in seeing their doctors as caring and omnipotent parents. His book does a brilliant job of attempting to get the medical community to know those chains and to rid itself of them by allowing a more adult-adult relationship to develop between doctor and patient. That the book stops short of taking the relationship to an even higher level along the continuum which he himself has plotted is no great criticism of what Professor Katz has done. Indeed, it is a form of criticism which attempts to build upon what Professor Katz has done and is therefore likely to be welcomed by him—even if he believes it to be mistaken.

In the introduction to the book, Professor Katz emphasizes that he views as preliminary the work which has been done on the phenomenon of informed consent. He observes:

These problems deserve study and their in-depth analysis must be extended beyond where I leave off. The more I reflect about informed consent the more I appreciate how many 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 (p. xx).

And at another point, he states: “This book’s ultimate purpose 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” (p. xxii). Thus the medium is the message. Constantly improving conversation among contributing discussants is what is needed to constantly improve the conversation between doctor and patient which is the subject of the discussion. For that effort, Professor Katz provides us with an exemplary role model—not only by the excellent work which he has done in helping others to know their chains, but also by the invitation he issues to have others show him his own.