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REVISIONISM MISPLACED: WHY THIS IS NOT THE TIME TO BURY AUTONOMY

David J. Rothman*

THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS. By *Carl E. Schneider*. New York: Oxford University Press. 1998. Pp. xxi, 307. \$39.95.

For the past twenty years, bioethics has exerted a profound influence on American medicine. Although its full impact cannot be precisely measured, one need only speak to European physicians and clinical investigators to grasp the full extent of the change. Americans may debate the sufficiency of the information that physicians share with their patients, but hear a European doctor exclaim angrily that it is criminal to ask a woman to decide whether to have a radical mastectomy or lumpectomy, and you know that bioethics has made a significant difference in the United States. So too, Americans, far more intensely than Europeans, will fiercely contest any proposed exception to informed consent in research protocols, and our Institutional Review Boards (IRBs) are unmatched for the protections they provide human subjects.¹

Not only foreign comparisons but daily events point to the difference that bioethics has made: consider the newspaper space devoted to bioethical considerations, whether the case be multiple births, AIDS testing in Africa, cloning, or organ donation, to choose recent examples; or the readiness of lawyers to have clients sign an advanced directive and proxy assignment; or the intensity of public debate on physician-assisted suicide. Bioethics has clearly become the stuff of referendum campaigns and dinner-table discussions.

To be sure, bioethics did not enter a vacuum. A powerful tradition of medical ethics goes back at least as far as Hippocrates.² But the two frameworks are dramatically different. For one, medical ethics was internal to the profession — physicians generally wrote

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1. See THE ETHICS OF RESEARCH INVOLVING HUMAN SUBJECTS (Harold Y. Vanderpool ed., 1996).

2. See Robert Baker, *The History of Medical Ethics*, in COMPANION ENCYCLOPEDIA OF THE HISTORY OF MEDICINE 852-57 (W.F. Bynum & R. Porter eds., 1993).

and read the salient texts. For another, medical ethics tended to focus on doctor-doctor relationships, not doctor-patient relationships. The early professional codes seem more intent on teaching etiquette than ethics — the most egregious transgression was to steal a colleague's patient. Ethical dilemmas at the bedside were resolved by the individual physician with little formal consultation with colleagues, let alone patients, and without a written record. The physician alone, and on his own, decided whether this case of pneumonia was the old man's best friend and should be left untreated. Finally, the principle of beneficence underpinned all of medical ethics. Physicians' concern for their patients' well-being, along with physicians' superior knowledge, rendered them better able to decide for patients than the patients themselves.

Beginning in the 1960s, and with mounting strength thereafter, bioethics altered each of these aspects of the tradition of medical ethics. Outsiders to medicine — lawyers as well as philosophers — pronounced on medical decisions, attentive to every nuance of practice and ready to tell doctors what to do or not to do. At the same time, decisionmaking on ethical issues became collective, evidenced by the emergence of IRBs and hospital ethics committees. It also became formal, that is, subjected to state and federal regulations and requiring written and signed forms, as in the case of "Do Not Resuscitate" orders.³ Perhaps most notably, patient autonomy became the guiding principle for decisionmaking. It was the old man who was now to decide whether the pneumonia was or was not his best friend. In effect, what had once been seen as beneficence came to be regarded as paternalism.

Although few would dispute the accuracy of this general sketch, one particular question is now very open to debate: Have Americans gone overboard in their dedication to the values of patient autonomy? Restated, have we replaced the tyranny of physician beneficence with a tyranny of patient autonomy? Have we let the letter of the law override the spirit? In the name of advancing the self-determination of patients have we imposed unreasonable and ultimately wrongheaded duties and obligations on them?

This is the central question that Carl Schneider⁴ addresses in *The Practice of Autonomy*, bringing to bear on it an exceptionally wide-ranging knowledge not only of law and bioethics but the social sciences as well. He has read widely in the relevant literature and comes away persuaded of the limits of the bioethics paradigm both in practice and in theory. His book is at once analytic and argumentative, building a case but sprinkling it with deprecatory asides.

3. See DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING 101-246 (1991).

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He announces at the outset that he is writing "against the grain," against "conventional bioethics wisdom" (p. xiii), which places excessive reliance on patient autonomy. He, a self-styled contrarian, claims to argue from the patient's point of view and promises to move us beyond "present pieties" (p. xiv) by demonstrating that patients want both more and less than autonomy. The tone is often grating, but the critical question is how well he succeeds.

Bioethics, Schneider contends, has endowed autonomy with such import as to make it "mandatory." Although the principle should remain central to medical decisionmaking, it has become "wooden," "simplistic," and "extravagant" (p. 33). It presumes a "hyper-rational" patient who, in a disembodied, abstract, coldly analytic, and bloodless fashion, calculates the advantages and disadvantages of one or another medical strategy, juxtaposes personal values against anticipated outcomes, and reaches a decision. But such is not the way of patients, Schneider insists. Quoting at length from poll data, sociological surveys, and the burgeoning literature of patient memoirs, he assembles examples of patients who did not want to make their own decisions. These patients, devastated by their diseases, sought guidance from doctors, and yes, were ready to take their advice on particular decisions. He also describes, in very effective fashion, the barriers to giving truly informed consent when suffering from major illness, medicated, and lying in a hospital bed.

Schneider's construction of the hyper-rationalist is familiar — we have met him before, albeit only in economic texts. There he takes the form of "economic man," who maximizes self-interest and utility, discounts all present and future benefits against present and future costs, and then invests, or expends, in cool and calculating fashion. Apparently, the bioethicists have brought him to medicine. The Hastings Institute and Georgetown have joined with the University of Chicago.

But the alliance seems illusory, and one wonders whether Schneider has invented a straw man. Most of his references to the hyper-rationalist, mandatory autonomy position come from would-be critics, not from advocates. In fact, I myself know of no one who pronounces him or herself in favor of such an approach. Thus, Dan Brock, who himself favors an "optional" model of autonomy — one in which the patient is entitled, but not required, to be active in medical decisionmaking — describes a "mandatory model" that compels people to make decisions.⁵ Schneider quotes Brock to document the reality of the mandatory autonomy school; Brock, however, is staking out a theoretical position, not critiquing an actual bioethicist. Schneider puts into the "optional" camp such lead-

5. See Dan W. Brock, *The Ideal of Shared Decision Making Between Physicians and Patients*, 1 J. KENNEDY INST. ETHICS 28 (1991).

ing bioethicists as Tom Beauchamp and James Childress and includes within it as well the autonomy position set forth by the President's Commission for the Study of Ethical Problems.⁶ So do hyper-rationalists really exist? The individual often invoked by Schneider, and this is the book's own distortion, is Jay Katz, a physician who has taught for many years at Yale Law School. In his 1984 book, *The Silent World of Doctor and Patient*, Katz was so eager to stimulate a dialogue between the two that he did, at times, exaggerate the need for patients to serve as decisionmakers.⁷ But Katz, as important as he is, does not constitute a school, let alone a movement. Schneider cites still other bioethicists, including William Bartholome and Robert Veatch, but again they seem to be more in favor of enhancing patient-doctor dialogue than of saddling individual patients with unwanted autonomy.⁸

Schneider is no more convincing in identifying instances of mandatory autonomy in patient narratives. To buttress his case, he tells the story of a patient, Daniel Cohodes, whose doctor

laid out the facts, shared the research literature, conducted computer searches on my behalf, and made certain that I sought appropriate outside expertise when necessary. It was painful at times, both for me and for him. The result is that I feel and believe that I am a full partner in any and all treatment decisions. [p. 15]

It is difficult, however, to see this as a coercive imposition of mandatory autonomy rather than as a wonderful example of a committed physician trying to educate and empower his patient.

Indeed, Schneider is so insistent on showing the drawbacks of mandatory autonomy that he goes out of his way to illustrate the seeming costs of a more general exercise of autonomy; in the process, he finds himself in very odd positions. At some points, he exaggerates the benefits of trusting doctors. So we learn that we often "enlist doctors to help get ourselves to do what we should" (p. 87). But as an example he cites an author who claims that when doctors order patients to stop smoking, "they do so more reliably and more comfortably" (p. 87). As anyone familiar with the recidivism rates among smokers knows well, such a claim has the most limited validity. Campaigns to stop smoking would be far more effective if all that was required was a doctor's order.

6. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (3d ed. 1989); PRESIDENT'S COMM. FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, REP. NO. 46, *MAKING HEALTH CARE DECISIONS* (1982).

7. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984).

8. See William G. Bartholome, *A Revolution in Understanding* 18 *QUALITY REV. BULL.* 6, 10 (1992); Robert M. Veatch, *Abandoning Informed Consent*, *HASTINGS CENTER REP.*, Mar.-Apr. 1995, at 5, 9.

In a similar vein, Schneider devotes considerable space to a critique of individual independence and a defense of dependence. He argues, on the basis of a handful of patient narratives, that individual independence works to subvert personal intimacy and fosters isolation. But there is no necessary connection between wanting to share fully in medical decisionmaking and, as Schneider claims, foreclosing friendship, forsaking reassurance, and, in a bizarre stretch of argument, being unwilling to accept a kidney donation from a relative (pp. 163-65).

Schneider's insistence that contemporary bioethics overburdens patients and that consent has turned into a hammer to bludgeon patients leads him to contend that we should now back off a dedication to autonomy in order to correct a deplorable imbalance. But without doubting that at times and in places some physicians might put too much of an onus on patients, and that some patients may be happier leaving decisionmaking to doctors, I cannot think of a worse time to retreat from a fundamental emphasis on autonomy. There are several reasons why.

First, the technical expertise of the physician is much greater than the patient's knowledge. Despite the world of internet patient chat groups, web sites, countless books for every known disease, and the weekly edition of the *New England Journal of Medicine* online, the odds remain strong that even well-informed patients will still do more listening than dictating.

Second, although I and many others spend significant hours in medical school teaching the need to foster dialogue and work with patients to obtain consent, it remains an uphill battle. I know of no medical school curriculum in which students spend as much time learning how to convey information as how to obtain information. The patient interview course is taught from one perspective: how to get patients to tell doctors what doctors want to know, not how to train doctors to tell patients what patients want to know.

Third, it is by no means clear what types of medical choices drive Schneider's argument. Late in the book, he lays out a grid that moves from technical decisions to preferential decisions; he also maps types of decisions, from one-time to continuous, and from treatment of potentially fatal diseases to ordinary diseases (ch. 4). He acknowledges the attraction of concluding that patients should make value choices and doctors technical choices, but aptly recognizes the difficulty — the impossibility — of maintaining the distinction in practice. Further, this sophisticated analysis is not well integrated into the overall presentation. Nowhere are these important differentiations brought to bear directly on the question of autonomy and decisionmaking.

Nor are we ever certain just how many patients are unhappy with the autonomy model, who they are, and how these differences should be reconciled. In whose interest are we to make policy? At times, Schneider concedes that he is worrying about a minority. At other times, it seems that the mandatory autonomy school is trampling over everyone's preferences. He acknowledges that "patients largely wish[] to be informed about medical circumstances," but "a substantial number of them do not want to make their own medical decisions, or perhaps even to participate in those decisions" (p. 41). Yet, he leaves the reader to parse out what is "largely" versus a "substantial number" and how these differences should be balanced.

Schneider does note that decisionmaking preferences vary significantly by class, age, and gender. Younger, well-educated women are far more likely to want both information and decisionmaking responsibility than older men and women with less means and less education. He contends, not unreasonably, that older patients making life and death choices are least likely to follow an autonomy model. But what he does not do is parse out the implications of this complexity for policy or education. Do we really want different standards of information sharing or consent, one for men and another for women? Or for those above or below 65? Or for those with advanced disease as against self-limiting disease? For patients with chronic disease as compared to acute disease? How should law, bioethics, and medical education differentiate between the need to respect the wishes of the young, well-educated woman who is determined to make treatment choices for her breast cancer and the less well-educated older woman who may want to leave these decisions to the surgeon? These are anything but trivial issues, and we need more guidance than his critique of mandatory autonomy provides.

Schneider's closing pages on the bureaucratization of medicine and the impact of bioethics are limp and unpersuasive. He recognizes that under managed care and team-based medicine, patients are losing authority to organizations as well as to physicians (pp. 186-95). Indeed, physicians are losing authority to the organizations that employ them, be they hospitals or HMOs. Although in his "against the grain" outlook, Schneider is not eager to condemn all aspects of bureaucratization, he does acknowledge that medicine today has the "impersonality of strangers" (p. 200). Patients and doctors do not choose each other, know each other, or stay with each other. But, however ready he is to fault bureaucracies for these outcomes, he is still more relentless in his critique of bioethics. Even more than for-profit managed care companies, it is responsible for the quagmire; bioethics ideology, apparently, is more powerful than the pocketbook. Because of bioethics' empha-

sis on autonomy and information sharing, it has seemingly become "easier for doctors to distance themselves from patients and to shed the psychic and moral burdens" that physicians once assumed (p. 205). Surely the indictment is exaggerated and is based on no more than a few anecdotes. In all events, Schneider and his readers are still left with the dilemma of how to proceed. Is this the time to abandon or reinvigorate principles of autonomy?

Schneider, ready to abandon them, looks for alternative answers in two distinct arenas. First, he champions the idea of guidelines. If only we had clear standards, in his examples, that emphasized the need for pain relief, for medical screening, and for end-of-life care, then doctors would know better what to do; further, patients would have valuable reference points that would reduce the burdens of choice. But Schneider forgoes a discussion of who is to compose the guidelines; surely HMOs, medical organizations, physician specialists, and consumer groups would be likely to provide very different content. Nor does he address whether guidelines would be effective in this new era. There is good reason to think not. After all, there are already existing guidelines on pain relief but no palliative-care specialist I know believes that they are being followed.⁹ And the same could be said of guidelines on medical screening and end-of-life decisions.

Rather than contend with these issues, Schneider closes his book with ten rules that are intended to enhance the place of kindness within medicine. Almost all of them, however, involve medical etiquette and not medical ethics. We have come full circle, with Schneider relying on manners rather than addressing power. Rule 1 for doctors: do not keep people waiting. Rule 2: respect privacy. Rule 3: introduce yourself to strangers. Rule 4: grant other adults the same courtesy in titles you accord yourself. His rules go on to urge saying "please" and "thank-you" and returning your phone calls (pp. 221-26).

Confronting the enlarged authority of managed care corporations that take their messages from their corporate clients, shareholders, and cost-conscious government officials (as in managed Medicare and Medicaid), no advocate for patient well-being can be confident of which protests or reform strategies will work best. These are times that make the most avid proponent of rights humble. After confronting a critique like Schneider's and reckoning with his solutions, pondering the arguments against autonomy and the potential of good manners to change structure, I, for one, am more prepared to invest in a rights-oriented movement, in patient and consumer proactivity and not dependence, and in patient au-

9. See INSTITUTE OF MED., *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 335 (1997).

tonomy, albeit optional rather than mandated. When physicians must see patients on a ten-minute schedule, and when financial conflict of interest is more acute now in medicine than ever before, I do not think it wise, in individual or policy terms, to worry about an excess of reliance on patient decisionmaking. Indeed, I cannot think of a worse time to champion the idea of passive patients.

It is not just managed care but the intrinsic character of medical progress that makes me so critical of Schneider's approach. There is every reason to assume that trade-offs in medical decisions are going to become more weighty than before. In almost all arenas, the progress in technique, skill, and capacity grows exponentially, both in terms of diagnostics and treatment. How far down the diagnostic road do we as individuals want to travel? As the power of genetic tools becomes greater — encompassing not only comparatively rare cases of fatal diseases such as Huntington's, but the more common cases of breast cancer, to say nothing of future capacities to diagnose heart disease, hypertension, or obesity — is the first and most critical message to patients to trust the genetic specialists? Is this truly the moment to worry about the perils of over-informing patients? With therapeutic interventions becoming more powerful, with transplant surgery long having broken the fifty-year-old barrier, with responsible surgeons ready to perform cardiac bypass or hip replacement surgery on men and women in their nineties, is the vital message to transmit one of excessive patient commitment to autonomy?

To put it most bluntly, Schneider's book is not one I would rush to put in an elder hostel or medical school curriculum, or give to legislators to ponder. Yes, some bioethicists should read it to make certain their normative statements on doctor-patient relationships are not exaggerated, and sociologists will profit from its intelligent discussion of the patient literature. But I think we need more, not fewer, books that instruct us carefully and precisely on how to protect and assert our own values and interests in the doctor's office.