

Book Reviews: How Bioethics Made Strangers Bedfellows

Albert R. Jonsen. *The New Medicine & the Old Ethics*. 1990. Cambridge: Harvard University Press. 171 pp. \$18.95.

William F. May. *The Patient's Ordeal*. 1991. Bloomington: Indiana University Press. 224 pp. \$24.95.

David J. Rothman. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. 1991. New York: Basic Books. 303 pp. \$24.95.

Robert M. Veatch. *The Patient-Physician Relation. The Patient as Partner*. Part 2. 1991. Bloomington: Indiana University Press. 320 pp. \$27.50.

HUMAN DRAMAS MAKE NEWS. A FAMILY STRUGGLES to force doctors and hospital administrators to remove—or to maintain—the feeding tube that is keeping alive their hopelessly brain-damaged relative. A woman conceives a child as a potential bone marrow donor for her dying daughter. Another woman announces that she is pregnant with her own twin grandchildren. As each story unfolds, “ethicists” are asked to comment in 20-second sound bites or pithy sentences. Remarkably, many of them manage to capture the essence of the issues in their allotted time or space.

Modern biomedical ethics was born in the 1960s, came of age in 1975 with the still famous case of the removal of Karen Ann Quinlan’s respirator, and has enlarged its focus to include, among other topics, the new infectious disease of AIDS, rationing of medical resources, and the project to define the human genome. This enlarged canon of problems has brought with it all the accouterments of academic specialization: professional societies, journals, conferences, and competition for grants, publications, and appointments. Bioethicists at a recent meeting discussed whether the various programs, centers, and specialists need a co-

ordinating organization to publish a calendar of events, lobby for funds, standardize and improve training programs, and facilitate participation in international meetings and advisory panels. They concluded that there are already enough organizations; what is really needed is an "association of associations."

Somehow, amid media glare and academic bureaucratization, the serious work of biomedical ethics does go on. In the past year, four of the most eminent practitioners of biomedical ethics have published books that sum up their current thinking and, taken together, present a varied picture of the field.

Of this quartet, only one author—Robert M. Veatch—writes in the style most often associated with biomedical ethics—analytic philosophy. Of the others, two—Albert R. Jonsen and William F. May—take religious studies as their starting point. David Rothman is a social historian of American institutions. Although the books tackle many of the same subjects, each author has a distinctive approach.

For ease of comparison, the books can be paired. Rothman and Jonsen look at contemporary medical ethics from historical vantage points, but come to apparently opposite conclusions about whether it is something old (Jonsen) or something new (Rothman). May and Veatch examine the patient-physician relationship from the patient's point of view, emphasizing the patient's subjective experience (May) and objective role as decision maker (Veatch).

Medical Ethics: Has Anything (or Everything) Changed?

Albert R. Jonsen's title summarizes his conclusion: *The New Medicine & the Old Ethics*. Jonsen, one of the first theologians to engage in bio-ethical discussion, is professor and chairman of the department of medical history and ethics at the University of Washington in Seattle. His book is an expanded version of the George Washington Gay Lectures delivered at the Harvard Medical School in 1988.

Jonsen describes himself as a "doctor-watcher . . . decorated only with degrees in philosophy and religious studies" (1). An "amateur historian," he found his literary genre, he tells us, in a religious tradition (not his own). He quotes a book review by Leon Wieseler as the source of his inspiration: "Most of the Talmud consists, not of *halakha*, or law,

but of *aggadah*, a magical rabbinic mode of thought in which myth, theology, poetry and superstition robustly mingle" (4).

The ruminations and reflections that comprise Jonsen's "secular ag-gadah" explore his thesis that the institution, practice, and profession of Western medicine are dominated by the paradoxical presence of altruism and self-interest. Self-interest because medicine offers great rewards—money, prestige, reputation, and gratitude—to its practitioners; altruism because the ideals and traditions of the profession stress service to humanity. Through medical licensure Western society grants physicians a monopoly on using hard-won skills for their personal advantage; at the same time the common good requires that these skills be used to benefit others.

Self-interest is grounded in ancient Greek medicine. As practiced by the Hippocratic physicians, medicine was a "skill, its practitioners were craftsmen, and their objective was a good living" (8–9). The early Christian church adopted care of the sick as a duty of charity. In the Middle Ages the members of the monastic order of the Knights Hospitallers of Jerusalem took on the noble mission of caring for "our lords, the sick"—pilgrims and crusaders on the trek to and from the Holy Land.

Jonsen distinguishes three traditions of medical ethics. In the Hippocratic tradition, only competence mattered. The essence of Hippocratic medicine was the idea that "all disease has a nature and arises from a natural cause, and is capable of cure." It is the physician's job to know by evidence and logic what leads to disease and to prescribe the right remedies. At the turn of the twentieth century, Richard Cabot, a physician at Harvard Medical School, took the ethic of competence to a new level. "Cabotean ethics" required physicians to respond to the personal and social needs of the patient as well as to master science and technique. Side by side with the Hippocratic–Cabotean ethics is the Samaritanian ethic—the principle requiring compassion and nondiscrimination in the provision of medical care.

From this broad historical viewpoint Jonsen's conclusion is not surprising: there are no new ethical problems in medicine, but only old problems in new formulations.

The new problems about genetics, transplantation, neuroscience, provision of services, and the like are new in their technical, social, and economic detail. They are old in the ethical outlines that were prefigured within the traditions: the outlines of limits to compe-

tence, finitude of compassion, protection of privilege, and propriety over skills. (134)

The new problems are puzzling, he says, not because they are new, but because they are "without roots in previous ethics of competence" (35). Almost all the problems faced by the old ethics could be resolved by the relationship between the physician and the patient, whereas the new "population-based" medicine threatens the patient-centered ethic. Population-based medicine, in Jonsen's framework, focuses on groups of people with similar disease characteristics or risks; an individual patient's care is determined by information gathered from the population of which he or she is only a representative. Jonsen cites the examples of burgeoning knowledge about links between genetic predisposition and disease, and the increasingly specific delineation of which patient groups are most likely to benefit from a particular intervention, say intensive care or transplantation. The result is that "in one after another of the conventional specialties and their sciences, the patient will be drawn into a population, seen as heir or progenitor of disease, or as participant in a pool of risk" (34).

As medicine moves in this direction, the old ethics face a challenge.

The intrinsic ethical limits to competence, based on undesirability of care from the patient's viewpoint or futility of care from the physician's, are no longer sufficient. Even if a particular patient should judge medical attention to be undesirable, we know that others in the relevant population may be affected by that refusal or need information or therapy that depends on the patient's decision [such as information about genetic disease that may be transmitted to future generations]. (34)

Jonsen's excursions into history and discursions on the practice of modern medicine are enlivened with stories, etymology, and myth, just as he promises. Perhaps he strains too hard to make everything fit his "old ethics" thesis. Something new is happening, as he himself acknowledges, but there are roots in the past. Moreover, even in the past, physicians did not always behave as their professional standard bearers commanded. Although the Christian physician of the 1500s was "obliged to remain in the plague-ridden city and to treat the poor without charge," many fled with their wealthier patients. Daniel M. Fox has pointed out that in later epidemics, such as the outbreak of yellow fever in Philadelphia in 1793, city officials offered financial incentives to phy-

sicians who stayed (see "The Politics of Physicians' Responsibility in Epidemics," *Hastings Center Report* 1986 [suppl: April/May, 5-9]). In this case the Good Samaritan became the Well-off Samaritan. Furthermore, the patient-centered ethic has been circumscribed by the concerns of others, in spite of physicians' resistance to governmental intrusion into the doctor-patient relationship. The Hippocratic vow of confidentiality has been breached, for example, to warn family members who might be exposed to disease or to report cases of communicable disease to public health authorities and gunshot wounds to police.

Whereas Jonsen takes on the panorama of medical history, David J. Rothman focuses on a single decade—1966–1976—which he sees as critical to a basic change in the substance and style of medical decision making. Key events were the publication in 1966 of Henry Knowles Beecher's indictment of clinical research ethics in the *New England Journal of Medicine* and the case of Karen Ann Quinlan in 1976, which brought to wide public and judicial attention dilemmas about removing life-prolonging technology from hopelessly ill patients.

Rothman, well known for his histories of American medical institutions, is director of the Center for the Study of Society and Medicine at Columbia University's College of Physicians and Surgeons. His central thesis is that in this decade "the discretion that the profession once enjoyed has been increasingly circumscribed, with an almost bewildering number of parties and procedures participating in medical decision making" (1). Hence his title, *Strangers at the Bedside*, and his subtitle, *A History of How Law and Bioethics Transformed Medical Decision Making*. These "strangers" include members of institutional review boards (IRBs) who review research protocols, hospital ethics committees, hospital risk managers, lawyers of many kinds, insurance company claim reviewers, case managers, government agency monitors, and many others.

The subtitle is misleading because nearly half of the book is devoted to the ethics of clinical research, not "medical decision making" as it is commonly understood. Rothman relishes the history of scandal, and he recounts in fascinating detail the history of Beecher's article and its examples of unethical research. He also provides—for the first time in print—the list of scientific articles from which Beecher drew his examples. (The original article contained no references, and Beecher steadfastly refused, on legal advice, to give them to anyone except the journal editors.)

From an initial focus on experimentation, Rothman turns to medical practice. He describes the erosion of the mutual trust and expectations

between doctor and patient that had characterized American medicine before World War II. The modern hospital, specialization of medical practice, the pace and complexity of medical technology all contributed to a disruption of any existing intimacy and shared outlooks. Rothman draws on literary examples to show the changing role of physicians in American society and the particular stresses they undergo. Other chapters recount controversies in organ transplantation and neonatal intensive care, the formation of national bioethics commissions, and the impact of the Karen Ann Quinlan case on decisions to remove life-prolonging technology. Written with Rothman's characteristic verve and attention to detail, these histories nevertheless are more familiar parts of the bioethics canon.

Although Jonsen and Rothman appear to reach very different conclusions, perhaps they are not all that far apart. Jonsen focuses on the individual physician's moral dilemmas; from that view, there is considerable continuity over the centuries. Rothman looks more deeply, but narrowly, at a particular historical moment. There can be no doubt that the kinds of external review and oversight that he documents have dramatically changed physicians' ethics as they prevailed at the end of World War II. The moral universe in which the traditional physician made choices consisted of the physician, the patient and/or the patient's family, the physician's peers, and only occasionally society's interests as expressed in the law. Today's physician may face philosophically similar problems, but the moral and legal universe is now peopled with many actors whose goals are often different and conflicting. If the field of bioethics got its impetus from the overweening authority of the physician, the next phase of its history may well reunite the physician and the patient in an alliance against the agents of cost containment who now wield so much power. In a recent conversation with a nurse about a terminally ill patient being cared for at home, I asked, "How long can he survive in this condition?" The answer: "The insurance company has approved him for two more weeks."

The Physician and the Patient: A Relationship in Change

The patient—a shadowy background figure in the books by Jonsen and Rothman—comes to the fore in the books by Veatch and May. The por-

traits differ considerably, however. Veatch is director of the Kennedy Institute of Ethics at Georgetown University. His book, *The Patient-Physician Relation*, is the sequel to his earlier volumes, *A Theory of Medical Ethics* (1981) and *The Patient as Partner: A Theory of Human-Experimentation Ethics* (1987). It is an updated and systematized collection of previously published essays along with new selections. Case studies, a hallmark of Veatch's work, are appropriately interspersed in the discussions. The topics are varied, including some of the most familiar but still unresolved issues in bioethics (the limits of confidentiality, disclosure of genetic information, the right of access to experimental drugs, Do Not Resuscitate orders).

He looks beyond the life-and-death situations typical of bioethical debate to the more mundane, but just as vexing, issues involved in, for example, treating a broken arm or hernia surgery. With characteristic precision, Veatch brings new meaning to commonplace occurrences. On leaving the hospital following an operation, a hernia patient is told, "Don't drive for a week." On what technical data is this advice given, Veatch asks. What is the risk of reopening the wound? How serious would that be? Even more to the point, what is the surgeon's expertise in weighing the patient's need or desire to drive against the technical data on risk? The Veatchian patient must be very self-aware and self-protective.

In reordering and summarizing his previous work, Veatch makes his basic position very clear: medical ethics is far broader than the ethical stances of physicians, either in groups or individually, when detailing prescriptions for their own behavior. The Hippocratic medical ethic, in which physicians acted out of beneficence as they determined their patients' best interests, is dead, and should not be resuscitated. In Veatch's conception, the relationship between patient and physician should be a partnership, in which both agree to work together, acknowledging their differing needs and agendas. Just as Veatch rejects the priestly, authoritarian model of the doctor, so does he reject the notion of the doctor as engineer or plumber, called in to do a job to the patient's specification.

Like Rothman, Veatch sees the modern doctor as a "stranger" to his or her patients, not, he is quick to point out, because "physicians are not warm, friendly, caring beings," but rather because "the institutional structure of the health system available to increasing numbers of people today dictates that care will often be delivered between strangers, for example, in inner-city clinics, rural health centers, student health services,

military and veterans' hospitals, tertiary care centers, and the offices of specialists . . ." (33). What ought to be the dominant model for the relationship? One possibility, Veatch says, is the "friend/physician"; another is the "stranger/physician." Veatch tests each of these models in terms of Hippocratic, contract, and covenant theories of medical ethics. Whereas the friendship model (suitably modified to fit the situation) accords well with a theory of medical ethics that stresses beneficence and shared understanding of what constitutes right conduct, it does not work for the more impersonal, impermanent encounters that typify medical practice. Veatch suggests that for some people, and for certain types of care, the stranger model may be preferable. This is, after all, the dominant model for psychotherapy, which involves sharing the most intimate of thoughts and actions with someone chosen precisely for his or her lack of prior association. The most trouble results when "strangers" try to act as "friends," that is, when doctors who have no knowledge or evidence about the patient's values, preferences, or wishes claim that they are acting in the patient's best interests.

Veatch's conclusion is, he acknowledges, radical: "Contemporary bioethics and its bedfellows in philosophy of science are bringing to an end what we can call the era of modern medicine" (264). The bioethics of the 1960s and 1970s contributed the recognition that "ethical and other values, not inherent in medicine, were necessarily involved in decisions to continue treatment on terminally ill patients, to perform (or refuse to perform) an abortion, to do a heart transplant, or to manipulate the genetic code" (268).

The critical shift from a modern to a "postmodern" conception of medicine involves a basic paradigm shift: in the new paradigm "every move of the health professional as well as the lay person in the medical sphere is an evaluative act." The modern medical paradigm is stretched in two ways. First, no part of science is value free. Earlier it was commonly argued, in the brain-death discussions of the 1970s, for example, that science could tell us whether a person's brain function was irretrievably lost; whether that person should be declared "dead" was a value question. Now, Veatch says, even the formulation of the criteria for asking "scientific" questions (for example, Do oral contraceptives cause cancer?) is recognized as containing value judgments. Second, "every move made by the clinician and patient" involves a value judgment; for example, the choice of pain medication—as well as how much and for how long—is not only a technical question, but also involves values about risk, suffering, and patient control.

Because evaluative actions pervade medical practice, what is needed now, Veatch says, is to match practitioners and institutions with patients of like value systems, particularly in areas such as attitudes toward terminal care, the extent of information sharing and consent, and obstetrical practice. Some selection on this basis is already going on; he cites the examples of Seventh-Day Adventist hospitals, the Oral Roberts Medical Center, and some feminist health clinics. (He might also have mentioned AIDS specialists and clinics, where providers and patients frequently share not only values about medicine and even sexuality, but also political views about confidentiality regulations, HIV testing, and public health policies.) In this system of health care delivery, institutions would make explicit their value commitments and policies so that both patients and staff that shared these values would be drawn to them. The "stranger/physician" would be more likely to be a "friend/physician," having chosen to serve in an institution that is committed to the patient's value system.

Although this sort of pairing is attractive to some people, others will find it impossible to implement, and still others will find the very idea incomprehensible. Many people (even physicians) are unwilling to assume so much responsibility for their own medical care; others simply do not have this luxury of choice, even if they have the determination and resources to identify, interview, and reach an agreement with like-minded physicians and hospitals. All the indicators for the future of medicine point to fewer, rather than more, choices. Although Veatch's ideal of a partnership of equals is a valuable standard, the basic thrust of bioethics—making health care providers more sensitive to the ethical dimensions of their work and to the particular values of each patient—is still necessary.

Whereas Veatch's writings portray the patient as moral agent, as rational decision maker, William F. May's collection of essays offers a different view of the patient (and patient's family). In *The Patient's Ordeal*, May, a professor of ethics at Southern Methodist University, seeks to reckon with their moral problems. Modern philosophers and theologians "like to identify quandaries that the decision-maker faces and then search for moral rules and principles that will help to solve or resolve these moral binds." Patients' ordeals do not involve solving problems as much as enduring them. "Health crises . . . confront their victims with things to do: but, far more profoundly, as such crises assault identity, they force their victims to decide who and how they will be" (5).

In describing the perilous journeys on which patients and their families are forced to embark through the vicissitudes of birth, accident, illness, abuse, reproduction, aging, and approaching death, May organizes his reflections around a series of categories: the burned, the retarded, the retarded institutionalized, the "gestated and sold" (surrogate babies), the battered, the molested, the aged, and the "afflicted" (people in institutions like prisons and mental hospitals). Two chapters explore the "afflicted assisting the afflicted" (Alcoholics Anonymous and organ donations). As May himself recognizes, categorizing persons as a series of past participles subsumes their individuality under their affliction. Someone so exquisitely sensitive to the nuances of languages could surely have substituted a different parallel formulation.

As May accompanies his subjects through their ordeals, he illustrates the broad and rich contributions of religion, literature and classical traditions to medical ethics. Along the way he informs us about, for example, the differences between the American and British schools of acting, the psychodynamic view of family violence, and the importance of room settings in homes for elderly people. Throughout he explicates the religious, explicitly Christian, viewpoint. He quotes Jesus, Yeats, Auden, Goffman, the Brothers Grimm, and the Greeks.

This is not a book of guidelines; it is a guide to the experience of enduring the unendurable.

Bioethics and Health Policy: The End of Individualism?

The ethicists of the 1960s and 1970s were, in Jonsen's phrase, "doctor-watchers." Jonsen, Rothman, Veatch, and May have all observed physicians in their native habitats. In fact, some of the most perceptive doctor-watchers are doctors themselves. The field of bioethics could not have developed without the active participation and, in some cases, leadership of many in the medical profession.

The ethicists of the 1980s and 1990s are, by contrast, economist- and court-watchers. The new medicine and the old ethics are facing the new economics. If doing ethics in the earlier period meant learning medical jargon, it now means understanding diagnosis related groups (DRGs), utilization factors, per capita expenditures, Medicaid thresholds, cost shifting, and the like. "Law and medicine," furthermore, are commonly

paired in symposia and discussions. The triumvirate of the future will undoubtedly be law, money, and medicine, with medicine a rather distant third. Autonomy is more likely to be discussed in terms of weighing physicians' rights against intervention by third parties, rather than patients' preferences against physicians' orders.

These volumes are not specifically addressed to health policy, although each of them touches on policy issues in some way. Rothman's historical account of the opening up of medical decision making to outsiders sets the context for challenging and monitoring medical costs. May discusses public policies on organ transplantation and surrogacy, as well as the institutionalization of elderly and mentally retarded people.

Jonsen and Veatch are most explicit about the values inherent in public policy decisions affecting medical care. In discussing what he calls the "full-blown problem of distributive justice," Jonsen extends his metaphor of the Good Samaritan. Where resources are limited, the Good Samaritan's essential ethical problem is "not whether to serve his own interest rather than those of the patient (he has already settled that by prior dedication to samaritanism), but whether to serve this patient so completely that future patients may be excluded from attention" (49-50). The central problem of gatekeeping, in Jonsen's view, is "the degree of certitude required to judge a procedure necessary or efficacious." Hardly any procedure, he says, is known to be "absolutely necessary or unnecessary"; hardly any technology is "proven to be absolutely efficacious or unefficacious" (55). In this view the question, Who shall be treated? must be preceded by a positive answer to the question, Is this treatment likely to work? A prospective patient must pass through not one but two gates to be admitted to the inner sanctum of care.

The three traditions he enunciates converge toward an ethics of justice:

The Samaritan recognizes persons in need. The Hippocratic enjoins only those treatments that are effective and beneficial. The Cabotean can make an informed decision about the nature and extent of that need and the means to remedy it. Together they point to the justification for a shift of moral probabilities from the absolute "Do everything possible for this patient" to the proportionate "Do everything reasonable for all patients." (58)

How this neat formulation could be translated into specific policies is not clear. Would Jonsen approve the Oregon plan for rationing Medic-

aid services as a justifiable attempt to provide everything reasonable for all (read *poor*) patients while allowing wealthier patients to obtain everything possible? In a different version of the chapter "Bentham in a Box," Jonsen appeals to a Rule of Rescue, in which the "imperative to rescue endangered life [cannot be] expunged from our collective moral conscience" (*Law Medicine and Health Care* 1986 [14]: 172-4). When the Rule of Reasonableness clashes with the Rule of Rescue, which should prevail?

Of the four authors, Veatch presents the most rigorously developed explication of the principle of distributive justice and the most specific prescriptions for implementing it. Three chapters address DRGs and the ethics of cost containment; justice and economics in caring for people who are terminally ill, in persistent vegetative states, or elderly; and voluntary health risks. Veatch concludes that "even after objectively useless and undesired care is eliminated, it is wrong to deliver all the possible medical care that really could be beneficial to and desired by patients" (179).

Decisions about kinds of care to be curtailed should not be made by clinicians, Veatch says, but by an insurance system that would exclude certain "marginally beneficial care that is relatively expensive." "Rational" insurance purchasers would probably forgo expensive, experimental terminal illness care that had a very low probability of success. (This seems intuitively correct, but is not borne out by the actions of many AIDS and cancer patients.) Probably also forgone would be care that staved off death but left a person in chronic pain, permanently severely impaired, or seriously compromised mentally, unconscious, or vegetative. Purchasers would forgo these types of care not because they have no net benefit, but because they are not "good insurance buys" (184). Rational insurance purchases would include pain relief and palliative care (even if expensive), nursing care, and possibly widely accepted chronic treatments of modest cost. No matter how rational such a system might be, it would not be ethical, Veatch says, unless it met both standards of procedural justice (ensured full, fair, and equal participation in the insurance pool in determining limits) and standards of substantive justice (protected the interests of the politically powerless, who might not be represented adequately).

Like Norman Daniels and Daniel Callahan, Veatch proposes an age-based criterion for determining marginally beneficial terminal and non-terminal care. He does not justify this choice on either completion of

the life span (Callahan) or age-specific opportunities for normal life (Daniels). Veatch believes that priorities for allocation of health care should be inversely related to age; that is, looking at a lifetime perspective, infants would have a stronger claim than adults who have completed a normal life span, but individuals who have recently completed a normal life span would have priority over substantially older persons.

Veatch's closely reasoned approach to this problem, whether or not one agrees with his conclusion, signals a new era of medical ethics, in which, as he puts it, "the principle of autonomy is nothing more than a footnote to a full theory of medical ethics. . . . The real challenge in medical ethics is deciding which version of community should dominate when our ethic turns social" (161). Is it the Judeo-Christian view, in which all individuals are seen as inherently equal? Or the Greek and modern libertarian views, which treat people as intrinsically unequal? At the social level, we need "an ethic that maximizes benefits within the constraints of the uniqueness of individuals as equals in their claim on social resources" (161).

If bioethics in the future is to assist in the development of a social ethic and public policy as forcefully as it has affected the individual physician-patient and investigator-subject relationship, it will first have to make clear the values inherent in public policy choices. Only then will it be possible to choose among various conceptions of "community," less often discussed in Veatch's principled terms than invoked as an ideological cover for advancing a particular group's agenda. All too often "community" means simply "me, my family, my friends, and people who agree with me." "Community"—inherently an inclusionary term—is frequently used in an exclusionary way. A true community may require sacrifices from its members for the common good, but it also opens its doors and shares its benefits.

In the process of incorporating collective values into medical ethics, the hard-won struggle for individual dignity and self-determination must not be sacrificed. "A cost-effective system of care that shuts out the dying or the elderly or the poor is morally deficient," says Jonsen (158). To which one might add: A notion of community as the basis of health policy that serves only to shore up entrenched professional, economic, or political interests is also morally deficient.

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