

BIOMEDICAL ETHICS

A Multidisciplinary
Approach to Moral
Issues in Medicine
and Biology

EDITED BY DAVID STEINBERG, M.D.

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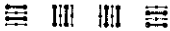
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6. See e.g., Kluger R. *Simple Justice: the History of Brown v. Board of Education and Black America's Struggle for Equality*. New York: Knopf, 1975; Echols A. *Daring to Be Bad: Radical Feminism in America. 1967-1975*. Minneapolis: University of Minnesota Press, 1989; and Filene PG. *In the Arms of Others: a Cultural History of the Right-to-Die in America*. Chicago: I.R. Dee, 1998.
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ALBERT R. JONSEN, PHD

Bioethics: Then and Now

Bioethics appeared in the world of medicine in the early 1970s, and as Allan Brandt rightly notes, has grown into a remarkably vigorous discipline. Professors of bioethics exist in most medical schools, courses are taught not only to medical students but to undergraduates, and a continual stream of books and articles is devoted to the topics of the field: death and dying, experimentation with humans, genetics and reproductive technology.¹ I must agree with Brandt that the form it has taken since its beginnings has stressed the relationship between physicians and patients, to the neglect of the structure of the institutions within which that relationship occurs. He proposes that “the bioethics that emerged in this period [from the 1970s until today] might not be a particularly good ‘fit’ for the range of moral and ethical dilemmas currently confronting American medicine.” I will, in this short commentary, explain why bioethics took the route that it did and suggest the route it must take in the coming decades if it is to become a better “fit” in the world of medicine and healthcare.

Brandt correctly identifies the starting point of bioethics’ journey: the “insular world of medical research and a paternalistic tradition in medical practice.” Persons encountered the medical world as patients or, much less frequently, as subjects of research. In both, physicians exercised great power. They held what one scholar called “professional dominance,” that is, they could decide what constituted disease, who might have access to treatment and whether that treatment was only for the patient’s benefit or for the

advancement of science.² Although physicians have been paternalistic and authoritarian throughout the history of medicine, the extraordinary transformation of medicine by science and technology has reinforced these traits. This was due, perhaps, to the very nature of science and technology. Science is arcane; scientists are masters of intricate information expressed in private languages. Technology is complex; only those with exact skills can apply it. Scientific knowledge and technical skill insures that decisions about its use and application will become the prerogative of its possessors.

Also, as medical knowledge became more scientific, it became incorporated in the insistent movement of science to acquire more, and more certain, knowledge. The practice of medicine was wrapped into the practice of research, and patients became, usually without their knowledge and consent, the subjects (or objects) on which the hypotheses of the scientists and the new treatments of physicians were tested. Medicine, through the first half of the 20th century, was proud that it had become "scientific," and certainly patients were the beneficiaries of many innovative discoveries that were translated into care. At the same time, those patients remained outside the process of decision-making that ultimately affected them deeply.

The occurrence of certain highly visible events, such as the Nazi concentration camp experiments and the American Tuskegee studies, were catalysts for debate over the ethics of experimentation. At the same time, many patients felt oppressed by the technology that prolonged rather than alleviated their suffering. Certain innovative interventions could save and prolong their lives, but at the same time, imposed severe constraints on the quality of those lives. Renal dialysis was one of these two-edged swords. Introduced in the early 1960s, it saved from certain death patients with permanently failed kidneys but confined them to a regimen of perpetual dependence on a machine and recurrent bouts of fatigue and dialysis-related illness. Many persons gladly bore these inconveniences; others found life with them to be intolerable. Some patients committed "dialysis suicide" by terminating or neglecting their regular treatment. New ventilatory techniques sustained life and breath but sometimes the light of life, in the mind and the affections, was dimmed or gone. The miracle technologies were not "fixes." They often imposed changes in the quality of life that persons felt they should decide to accept or reject. Gradually, in medical care and in research, the idea of informed consent emerged as a legal standard. The technology that had reinforced the paternal authority of physicians became an instrument that patients could decide to employ in their own behalf.

Bioethics appeared within that social context: technology giving physicians more power to treat than they had ever possessed; patients feeling the need to control the effects of that power in their lives. However, the initial

bioethicists were not, for the most part, physicians. They were theologians and philosophers: scholars with a knowledge of academic ethics but only observers of medicine (except when they, like most mortals, became patients). They appreciated the need for scientific advance but deplored the depreciation of the freedom of persons who were the sources of that advance, namely, the experimental subject.

Theologians of note, such as Paul Ramsey of Princeton, and philosophers of repute, such as Hans Jonas of the New School of Social Research, undertook to revise the ethics of medicine in ways that would counteract medical authoritarianism and paternalism.

These scholars, and those who followed them, introduced into medical ethics a quite novel view. Those who practiced medicine had constructed medical ethics. These practitioners reflected on the personal and social conditions that would conduce to a successful healing and a successful practice. Only rarely did they employ the concepts and the methods of the philosophers and theologians who ruminated on the moral life. However, the first bioethicists were formally trained in those concepts and methods and explicitly brought them to the analysis of the new questions about medical authority and about life and death.³ Ramsey drew on theological notions of covenant, the mutual compact between Yahweh and the People of Israel, to frame a notion of covenantal fidelity between doctors and their patients, research scientists and their subjects. Jonas imported notions of classical European philosophy into his development of the ethics of responsibility between scientists and subjects. Other theologians and philosophers who entered the bioethical debates evoked ethical arguments from their disciplines. In general, those arguments emphasized the freedom, authenticity and responsibility of individuals. They slighted the broader settings of politics, economics and culture within which human actions take place because, at that time, their disciplines attended much more to personal action and inter-personal relationships than to social structures and institutional structures.

In the ensuing years, the perception of the nature of the problems of bioethics has shifted from the interpersonal (which is still important) to the institutional. The authority of medical managers has usurped the authority of physicians and the rights of patients. The use of technology is contingent on policy and financing as much, or more, than on medical need. The rights of patients are debated now, not just by philosophers, but also by congressmen whose opinion is deeply colored by political ideology. It is clear that the broader social and institutional contexts are crucial to understanding and ameliorating ethical problems. Contemporary bioethicists have recognized the overemphasis on the ethics of autonomy and desire a richer appreciation of the ethics of justice. They are working at the reconstruction of a discipline that will have stronger conceptual tools to

pry open the problems created by the social and economic structures of modern health care. However, this is a work in progress and, with few exceptions, bioethics does not yet “fit” these problems in the same way that the early bioethics “fit” the problems of emerging technology.

I have written about bioethics as a discipline, that is, the work produced by scholars employing shared methods of analysis and using specialized terminologies to express the results of their analysis. However, there is another bioethics. It exists in the media, in political debates, in the meetings of hospital committees, in the anxious discussions of patients, families and doctors over treatment and care, in the corporate planning of biotechnology companies and in many other places. This is not a bioethics of formal concepts and analytic methodology. It borrows bits and pieces from disciplinary bioethics, talking about informed consent, risks and benefits, equity, rights, and the like. It knows something of the issues, such as physician-assisted suicide, genetic therapy and cloning. But it is a bioethics carried on by concerned people, aware of the problems and desirous to see them resolved in some fashion. This is the discourse of bioethics rather than the discipline. The questions asked by Brandt about the deeper impact of bioethics are, as he said, answerable only by a fuller assessment. However, it seems to me that these questions are much more vigorously discussed in the many settings of bioethical discourse than ever in the past. Some of that discourse has led to specific social change, such as the enactment of Oregon’s law about physician-assisted suicide and the same state’s policies on the rationing of healthcare resources. But even where specific evidences of change are absent, the problems are broadly and openly and intelligently discussed. In the long run, bioethics as a discipline is justified to the extent that it introduces into public discourse ideas and ideals that, through the means open to a democratic society, move social, institutional and economic powers in directions that better reflect those ethical ideas and ideals.

NOTES

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