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Medical Science Needs to Partner with Ethics

Bioethics helps us understand technologies and then set medical priorities.

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Review of Everybody Wants to Go to Heaven but Nobody Wants to Die: Bioethics and the Transformation of Health Care in America. By Amy Gutmann and Jonathan D. Moreno. Liveright Publishing Corporation. 272 pp. $27.95

Bioethics emerged as a field of study – and a profession – in the 1960s and ‘70s. Responding to Vietnam War “credibility gaps,” civil rights protests for equal rights; Medicare and Medicaid costs; and revelations about syphilis experiments on blacks in Tuskegee, Alabama, bioethicists hoped to insure that debates about medicine and health care were based on publicly defensible facts and values. In the ensuing decades, their plate has been quite full.

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In *Everybody Wants to Go to Heaven but Nobody Wants to Die*, Amy Gutmann, a political theorist and the president of the University of Pennsylvania, and Jonathan Moreno, a professor of medical ethics and health policy, the history and sociology of science, provide a superb introduction to bioethics. Gutmann and Moreno (who served on President Obama’s bioethics commission) assess dozens of “hot button” issues, including abortion; the right to die; the right to try (experimental drugs and treatments); buying transplantable organs; designer babies; cloning; human-animal chimeras; and synthetic biology.

Accessible, informative, and judicious, *Everybody Wants to Go to Heaven* avoids easy answers. The authors advocate an approach to medical research and health care that draws on the “bioethics mantra” – autonomy, nonmaleficence, beneficence and justice – and balances the rights and needs of individuals with those of society as a whole. They place special emphasis on access, affordable, and doctors’ duty to tell their patients the truth.

That said, Gutmann and Moreno invite us to think hard about ethics in medicine. Drug prices can be brought down, they indicate, if the federal government empowers Medicare, the single largest payer, to negotiate with pharmaceutical companies. However understandable (given the cumbersome procedures of the FDA and the sense of urgency of people with terminal illnesses), right to try laws, they suggest, have stood the principle of patient autonomy on its head by privileging a right “to demand an unproven treatment.” Markets in human organs unjustly exploit the poor, Gutmann and Morena argue, in part because the bargaining conditions are unequal, but primarily because sales of body parts are “degrading to personhood.” But, they add, the commodification of human beings should be weighed against the chance of saving lives through a regulated market offering informed, healthy, and financially stable individuals some remuneration for donating a kidney to a stranger.

Even more controversially, Gutmann and Moreno balance misgivings about the specific traits prospective parents desire in “designer babies” with “our attitude toward age-old practices of selective mating by choice for the purpose of procreation.” After noting President George W. Bush’s request that Congress prohibit the “most egregious abuses of medical research,” including the creation of human-animal hybrids by fusing genes from two species, the authors write that “the picture becomes less creepy” when we understand that “chimeric” animals are used to study the feasibility of stem cell treatment of Parkinson’s Disease, strokes, leukemia and AIDS.

*Everybody Wants to Go to Heaven* concludes with a summary of the Obama Commission’s assessment of the “appropriate ethical boundaries” of the uses of synthetic DNA. The commission’s open hearings, Gutmann and Moreno indicate, yielded a wide range of viewpoints, from “let the science rip” to objections to bio-error, bio-terror, and playing God. Uneasy about the risks, the commissioners made clear that scientists must not be permitted to treat the natural world as a “blank space to be filled by whatever they wish.” That said, they recommended “prudent vigilance” facilitating a pursuit of three social values: “the intellectual freedom of synthetic biologists as they seek to realize the potential public benefits of revolutionary technologies; but with established oversight mechanisms that monitor and mitigate risks over time to ensure responsible stewardship of our planet.”
The devil, of course, will be in the details. As it will be for all aspects of bioethics. But Amy Gutmann and Jonathan Moreno have given us a basis on which to understand – and help regulate – technologies that require us to set priorities, make trade-offs, and monitor results.