

Book review of “bioethics in action” Cambridge University Press

Review of bioethics in action, edited by Françoise Baylis and Alice Dreger, Cambridge, UK, Cambridge University Press, 2019, paper, vii, 177 pp.

Bioethics is a late 20th century field that grew out of philosophy and applied medical ethics. Philosophy transcends disciplinary turfs. Those trained in the history of ethics translate their theoretical knowledge to address practical ethical problems in the fields of biology, including genetics and neuroscience, environmental sciences, human and animal experiments and ecology. Medical ethics draws people from applied philosophy and medicine.

Before bioethics became an academic discipline, the issues bioethicists addressed grew out of international law and treaties, such as the Nuremberg Trials and the Geneva Convention, advances in medical technologies, as in keeping comatose patients alive, and from national scandals arising from experiments on human subjects, such as the Tuskegee affair.

Unlike traditional philosophers, bioethicists were intent on reaching people outside their discipline to critically evaluate norms of human behavior. To achieve this goal, they organized centers, published in popular magazines, and participated in the development of interdisciplinary journals. The field was largely idea driven with contributions from academic philosophers and physicians.

Bioethics in Action, edited by Françoise Baylis, professor of bioethics and philosophy at Dalhousie University and Alice Dreger, a historian of science, medicine and sexuality and popular writer, looks at the activist side of bioethics. In their introduction, they distinguish between “punditry bioethics” and “bioethics-based advocacy.” The book consists of eight chapters of personal stories by bioethicists who were drawn to take activist roles in order to change policies or to raise the consciousness of medical or public health practitioners.

While the book is titled “Bioethics in Action” it could very well have been titled “Activist Bioethics” since the chapters are reflections of the personal stories of authors confronting systems of care that neglected ethical considerations in deference to commercial interests. I shall highlight a few of the chapters in this review that illustrate the book’s primary goals and that distinguish this volume from other writings in bioethics.

Co-editor, Alice Dreger, discusses her advocacy work in a chapter titled “Twenty Years of Working toward Intersex Rights.” Children born with ambiguous sexual organs, referred to as intersex infants, were traditionally assigned a sex through surgical methods. Sexual assignment of intersex infants placed no consideration on how a child would feel when they matured. Too often it was the interpretation of the sex assignment by the surgeon urging parents to accept the surgery.

Dreger describes giving up her tenured professorship at Michigan State University to devote herself to educating parents and the medical community of the harm that childhood sexual assignment had inflicted on the family. “... in over twenty years, not a single intersex person has come out publicly to say that they are glad their parents elected early surgery for them.” (67)

Dreger explores the challenges a person like herself with a Ph.D. who was not an intersex individual had in getting her ideas accepted by physicians and members of the intersex community. She ends the chapter with a bioethical dilemma: Do parents have a right to determine whether their intersex child should undergo sexual assignment through surgery? Is intersex a medical abnormality or a difference in sexual development?

A second chapter written by distinguished bioethicist Ruth Macklin describes her work with the Hastings Center and Public Citizen's Health Research Group. Macklin began her career in the philosophy department at Case Western Reserve University. Subsequently, she joined the faculty in the Department of Epidemiology and Population Health at Albert Einstein College of Medicine in New York. At the time, Medical Schools were beginning to introduce medical ethics in the curriculum as they also fulfilled federal guidelines requiring institutional review boards (IRBs) for approving human experiments. Macklin's case study involves the inadequacy of informed consent documents in the treatment of severely premature newborns in a clinical trial. The federal Office for Human Research Protection (OHRP) reported on the failure of a clinical trial investigation to disclose important information about the risks to extremely premature infants involved in a trial but took no action against investigators. The controversy erupted in the pages of the *New England Journal of Medicine*.

Macklin describes her collaboration with Public Citizen to bring the issue before the medical community in the face of a "don't rock the boat" mentality. At issue was the lack of independence of OHRP from the influence of the National Institutes of Health, which chose not to act on the informed consent allegations.

A third chapter I shall highlight in this review is by Joel Frader, a pediatrician at the Feinberg School of Medicine, Northeastern University. I was particularly moved by Frader's chapter titled "Establishing Pediatric Palliative Care: *Overcoming Barriers*" because it brought to mind a medical ethics seminar I co-developed and moderated at the Tufts School of Medicine. A physician colleague and I ran a bioethics series where we invited clinical physicians to discuss a medical ethics dilemma they had faced in their practice. An invited pediatric oncologist discussed a case of a young child who had undergone a number of failed cancer treatments to address the aggressive disease. He told the child's parents that their child's prognosis was grim and that he had nothing more to offer to address the advanced disease. The parents were insistent that the doctors should not stop trying to cure their son. The physician said that there were very aggressive experimental treatments that had a very low probability of success. The parents responded, "what do you call a low probability?" The physician said, "5% chance at best." The parents fired back: "That's not low to us . . . we expect you to make every effort to save the life of our child." The physician responded that under these treatments the child would incur painful side effects that do not justify the low probability of success. In the case of life-threatening pediatric disease, who makes the choice about whether "enough is enough?"

This brings me to Frader's chapter. He describes his experiences caring for children with life threatening illnesses. What he learned was that "even as medicine and nursing began developing palliative and hospice care for adults in the United States, few seemed interested in palliative and hospice care for children . . . nobody wanted to focus time or energy on improving the experiences of dying children and their loved ones." (127).

Because there had been successes in saving children from childhood illnesses, Frader describes an ethos that developed among pediatric physicians that no child had to die. This led to no limits on rescue "even when the burdens of continuing efforts seemed too much for particular children to bear." (129). Frader's advocacy, which proved somewhat

successful, was to introduce palliative care consultation for children facing grave prognoses.

If there is one contribution missing in this collection, it is the years of advocacy by bioethicists to create awareness and policy changes on the abuse of mentally ill patients in clinical trials. First, it required the investigation of patient outcome data from the psychiatric literature to illustrate the abuses. In one study the authors wrote: “... we and others have raised concerns about the ethics and propriety of the use of persons with mental illness in high risk research on human subjects (Shamoo, Irving, and Langenberg 1997).” The topics addressed by bioethicists included: inadequate concern for the vulnerable status of patients; invalidity of informed consent; lack of accurate and sufficient information to the subject; and the lack of integrity of the reported data. These abuses overlap those discussed in the book’s chapters.

Second, bioethicists brought the issues before federal bodies such as the National Bioethics Advisory Commission (NBAC) by providing testimony in public hearings. The bioethicists who testified before the NBAC sought a prohibition of using the mentally ill in research protocols when the research could easily have been performed on another population. They argued before the Commission that “narrowly defined nontherapeutic harmful and degrading experiments on the most vulnerable segment of our society” should not be done, (Shamoo 1999) and that a person has the right to decline participation in a clinical trial even if the person is severely impaired. Moreover, an independent, qualified professional should be available to assess the potential subject’s capacity to consent.

Notwithstanding some neglected issues, what makes this collection of essays unique and engaging is that they are written in the first person and describe the experiences of bioethicists and physicians who have raised awareness and changed policies on some of the major bioethical issues of our times. They have taken the issues from the pages of journals to the front lines of social change. This volume can be useful for courses on medical and public health ethics.

References

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