Duty and healing: the lifework of Benjamin Freedman

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Résumé

BENJAMIN FREEDMAN, un des plus grands bioéthiciens du Canada et universitaire reconnu sur la scène internationale, est mort le 20 mars 1997. Professeur de médecine à l'Université McGill de Montréal, Freedman a beaucoup contribué au domaine de la bioéthique, où il a fait notamment des travaux fondamentaux sur le consentement éclairé et la compétence. Dans le domaine de l'éthique de la recherche, Freedman est l'auteur du concept de l'équivalence clinique comme condition préalable à l'exécution éthique de recherches cliniques. Des travaux subséquents ont clarifié l'analyse éthique du risque et les limites du risque permissible en recherche sur les enfants. Parmi les travaux récents de Freedman, mentionnons un ouvrage d'analyse sur le judaïsme et la bioéthique.

Benjamin Freedman, professor of medicine in the Biomedical Ethics Unit at McGill University, Montreal, and one of Canada's foremost bioethicists, died on Mar. 20, 1997. Well respected in Canada, Freedman was also an internationally renowned scholar who made fundamental contributions to our understanding of the ethics of clinical practice and research. In his 20 years as an academic and clinical bioethicist, Freedman authored a large body of work, including 6 books and monographs as well as 122 articles. His opus comprises important contributions to our understanding of informed consent, substitute decision-making, competency, obligations of health professionals, the ethics of research and the lessons of the Judaic legal tradition for the field of bioethics.

Freedman's early work focused on challenging and clarifying the concepts of informed consent, surrogate decision-making and competency. A unifying theme runs through this work: the moral obligation of health care professionals to respect patients and their capacity for rational decision-making. If this principle is to be upheld, Freedman argued, physicians have a duty to recognize valid consent.[1] However, in the case of incompetant patients, how shall we decide for them? Freedman argued against the predominant hypothetical test — what the person would have wanted (After all, who could know?) — in favour of a "best-interest" standard of judgement.[2] In a critique of standards for competency, Freedman proposed the novel standard of "recognizable reasons," by which a person is deemed competent if he or she can supply reasonable premises to support a practical conclusion.[3] For example, unwillingness to risk impotence is a recognizable reason for refusing prostatectomy for cancer, whereas the belief that the operation will interfere with productivity as an accountant (a false premise) or the fact that it is Monday (a non sequitur) are not recognizable reasons. Freedman's recognizable reasons standard for competency was later adopted in a US Court of Appeals judgement.

Subsequent work examined the obligation of health care professionals to treat patients infected with HIV.[5] The problem was how the physician's traditional freedom to refuse to accept a patient could be reconciled with the circumstances of HIV infection, an epidemic that disproportionately affects marginalized groups, including gay men and intravenous drug users. Freedman's answer was to recognize that "a right to refuse a patient for no reason whatsoever does not imply a right to refuse a patient for any reason whatsoever. In other words, a right to arbitrary action does not imply a right to invidious discrimination."[5] Physicians, therefore, may not refuse to treat patients solely on the basis that they are infected with HIV.

Editorial

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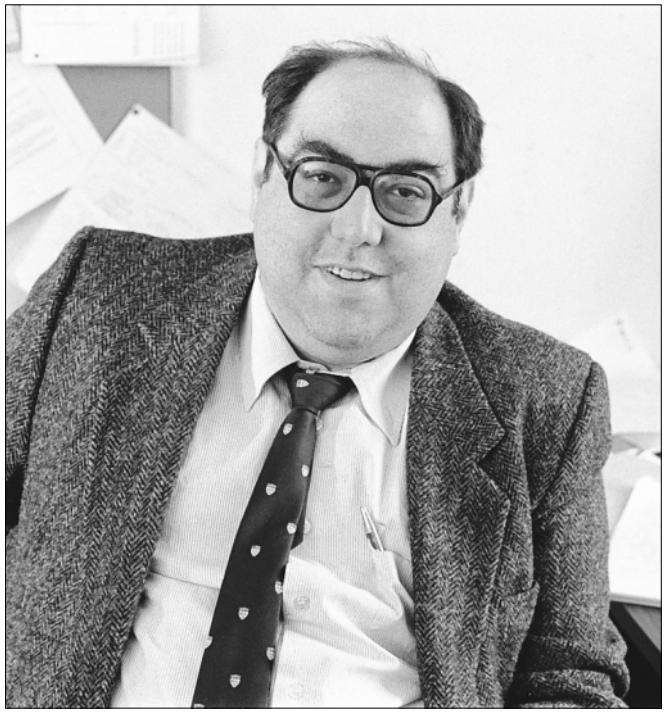
Perhaps best known is Freedman's work on the ethics of human experimentation and, in particular, the concept of "clinical equipoise." The concept of clinical equipoise addresses the question When can human subjects be enrolled ethically in a trial of experimental therapy? A state of clinical equipoise — "honest disagreement among expert clinicians" about the preferred treatment — must exist at the initiation of a study. In other words, one component of the ethical permissibility of a clinical trial is that at its start there be "no consensus within the expert clinical community about the comparative merits of the alternatives to be tested."[6] This principle has profound implications for the conduct of clinical research. For example, equipoise does not allow the use of placebo controls when "proven-effective" therapy exists; by definition, such therapy is known to be superior to placebo.[7]



Benjamin Freedman (1951–1997)

Freedman's vision of the ethical analysis of clinical research was comprehensive. To date, the ethics of clinical research has developed in reaction to scandal and, thus, in response to the question How can this particular evil be avoided? Once ethics is seen as the evaluation of human choice, the scope of its inquiry in research expands dramatically: "What will be tested? How will it be tested? Who will be tested? How will [subjects] be recruited? When will the test be complete?"[8] Ethical questions in research are no longer restricted to narrow aspects of the protocol (e.g., the consent form) but, rather, are seen to permeate the design, conduct and (even) reporting of research. The ultimate goal of research ethics is to improve the conduct of clinical research and thereby clinical practice. In order to pursue these questions, Freedman and his colleagues Drs. Abraham Fuks and Stan Shapiro founded the Clinical Trials Research Group at McGill University in 1991. They were later joined in this venture by Dr. Kathleen Cranley Glass, Dr. Karen Lebacqz, Myriam Skrutkowska, Trudo Lemmens and myself. Important work emanating from the group includes a systematic approach to the analysis of risk in clinical research.[9] According to this approach, risks associated with therapeutic procedures are weighed separately from nontherapeutic risks (that is, risks incurred solely to answer the scientific question and without therapeutic intent). Therapeutic risks must satisfy the principle of clinical equipoise; nontherapeutic risks must be balanced by the importance of the knowledge that may reasonably be expected to result from the study. As an example, we may consider venipuncture done in the context of a study involving experimental chemotherapy. Venipuncture done as a part of the clinical care of the study participant — perhaps to check the white-cell count during a course of chemotherapy — is ethical when the therapeutic index of the treatment overall (i.e., including the chemotherapy) compares favourably with standard treatment and with the other treatment arms (if any) within the study. Venipuncture performed only to answer a scientific question — perhaps to check the blood level of the chemotherapy drug — is justified if the information cannot be gained in another, less invasive, manner and if the knowledge that may derive from it justifies the risk. Further work defined limits on the degree of nontherapeutic risk to which subjects, particularly children, may be exposed.[10]

Freedman's most recent major project and, I believe, the culmination of his lifelong exploration of the nature of human obligations, was a book-length examination of Judaism and bioethics. Entitled *Duty and Healing: Foundations of a Jewish Bioethic*,[11] it analyses a number of contemporary issues in bioethics, including substitute decision-making, informed consent, competency and acceptable risk, using sources in Jewish law, or Halacha. For religious Jews, this book holds a special significance; for others, it offers a refreshing opportunity to examine a duty-based moral system distinct from the rights-based system that pervades contemporary bioethics. Consider a case involving a family in which there is disagreement as to the preferred treatment for an incompetent family member.[12] A rights-based approach has a decided procedural focus; it asks Who has the right to decide for this person? A duty-based approach reframes the problem —

usefully, I think — in terms of the obligation to care for a family member and provides considerable substantive detail on that obligation: What obligation does one family member have to another? What are the limits of this obligation?

Like any master, Freedman had a distinctive voice — one knows when one is reading something written by him. His work was philosophical yet in-the-world; principled yet allowing of exceptions; rigorous yet compassionate. Freedman saw the task of bioethics in part as "the exposure of muddled and wrong-headed concepts, to clear the way for a healthy growth of ideas."[3] In his work, he not only cleared the way but also provided ideas to fill the gap. Freedman's ultimate accomplishment lies in the fact that his vision of duty and healing challenges us, both professionally and personally, to strive for moral excellence. In our struggle to become better clinicians, researchers, teachers, bioethicists and, in the end, better human beings, we honour the memory of Benjamin Freedman.

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