

## Where do we go from here?

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**Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making.** By David J. Rothman. *Basic Books: 1991. Pp.320. \$24.95.*

IN 1964 the World Medical Association produced an important statement on human experimentation, now known after the city where the meeting took place. The Helsinki Declaration was itself an updated version of the 'Nuremberg Code' formulated soon after the postwar revelations of the experiments in the Nazi concentration camps. Despite the code, however, by the late 1950s reports in medical journals were suggesting that ever more nontherapeutic research was occurring without the informed consent of the patients concerned. The new declaration emphasized that such consent was vital, and in Britain official bodies quickly produced guidance documents. But three years later the focus in Britain sharpened considerably: in *Human Guinea Pigs* (Routledge, 1967) a book expanded from a 1962 magazine article, Maurice Pappworth, a London physician, argued that the ethical problems arising from human experimentation had become crucial. Giving references documenting a large number of studies in children, pregnant women, prisoners, the dying and the old, among others, he pressed for two developments. First, research should be carried out only in true volunteers, and, second, one vital safeguard for patients would be the return of the 'physician-friend'.

Like all whistleblowers, Pappworth encountered much opposition from his fellow professionals, although the debate produced results. Every UK health authority established a research ethics committee and a new society of medical ethics set up groups in every medical school, and a journal and bulletin. And the appearance of advice documents and the wider debate have continued, with Ian Kennedy's 1980 Reith Lectures. *The Unmasking of Medicine* (Unwin Hyman, 1981), being followed by more professional hand wringing and sharpening of the issues. Elsewhere also there have been similar debates and solutions, particularly in the Nordic countries.

Regrettably little of this is recorded in David J Rothman's *Strangers at the Bedside* — although he concludes that possibly in the

■ Two books of archaeological interest are *The Passage of Arms: An Archaeological Analysis of Prehistoric Hoards and Votive Deposits* by Richard Bradley (published by Cambridge University Press, £30, \$44.50) and *The Vikings* by Else Roesdahl (Allen Lane, hbk £17.99, \$26.95; pbk £5.99, \$7.95).

United States the revelations at the Nuremberg trials were perceived as irrelevant. Thus his book is virtually — though not explicitly — limited to events in the United States. This lack of an international dimension diminishes an authoritative and beautifully written book. My reaction is not that of the Czechs in 1938 — bewailing Neville Chamberlain's dismissive "far off country of which [Britons] know little." Rather, an examination of the debates and differing solutions elsewhere might have teased out the possible reasons for them and thrown more illumination on the questions Rothman discusses. For example, with their comprehensive system of good general practice, Britain and Denmark now have what Pappworth proposed as one solution: a physician-friend for the patient — whereas in Sweden patients have unrestricted access to a specialist. Yet of the three countries it is Denmark that has experienced the greatest public furor over ethical issues, and one can only speculate on the reasons.

But, this said, Rothman's account is first class. It reads well, as befits an account by a historian who is also a professor of social medicine. His subtitle, *A History of How Law and Bioethics Transformed Medical Decision Making*, suggests his theme: the mid 1960s to 1970s were critical in the evolution of bioethics. During this time doctors' discretion became increasingly circumscribed by institutional review boards, Food and Drug Administration regulations, and a Patients Bill of Rights while other professionals appeared — lawyers, philosophers, and sociologists. As a result both the style and the substance of decision making have been transformed, and the patient has a new friend in the bioethicist — a relationship, Rothman points out, that now crosses class barriers.

One man who started it all, Rothman's protagonist, Henry Beecher, was the third driver of the founding troika (the others being Pappworth and Hugh Clegg, editor of the *British Medical Journal* and behind the Helsinki Declaration). In 1966 an article in the *New England Journal of Medicine* by Beecher, a Harvard professor of anesthesiology, recorded 22 examples of ethically dubious human experimentation. Even before its appearance the account was an obvious hornet's nest. Beecher's previous presentation at a conference excited media attention and also led two Harvard colleagues to refute his views at a press conference. And initially the *Journal of the American Medical Association* had rejected the article, with two adverse referees' reports, while, on the advice of legal colleagues, Beecher omitted the references documenting these studies (printed in Rothman's book for the first time).

There were other reasons why concern over human experimentation surfaced at this time. For Rothman is on firm ground in showing that in the 1960s all professions came under threat, the thalidomide tragedy

destroyed illusions about continuous progress in medicine, and the reception of Rachel Carson's *The Silent Spring* (Hamilton, 1962) testified to a deep public suspicion of science. And a further major reason was a perceived change in doctors themselves. Until 1945 — many had practised little differently from their earlier fictional counterparts — George Eliot's Lydgate, with his professional pride, and Chekhov's Dr Askov exhausted from combating a typhus epidemic. After the war the generalist, a well-liked local figure, became reluctant to do house calls and, with the dominance of Medicare and Medicaid, was seen to have become preoccupied with his bank balance. Indeed, the generalist all but disappeared, to be replaced by an impersonal specialist working with frightening machinery in a distant institution and having scientific kudos as his priority.

The screw of public suspicion was turned a whole revolution by alarm over organ transplantation. Unlike patients with kidney disease, where dialysis was a feasible alternative, those with some forms of heart or liver disease had no alternative treatment. The need to obtain organs for transplantation from cadavers led to an obligation to define brain death, an agonizing process emphasized in Britain by the furor over a British television programme querying whether organ donors were really dead. And increasingly in the United States clinical dilemmas came to be decided not by doctors but by ethics committees or the courts. Thus in a series of lawsuits over noncompetent patients, the courts went against the relatives' wishes, ordering, for instance, the surgical treatment of a newborn with severe malformations and the continuance of artificial ventilation in a young brain-dead woman.

David Rothman's book largely ends in the mid 1970s, although in an epilogue he emphasizes the valuable role of the US president's commission for the study of ethical problems. Given that this could have issued guidance in the new ethical debates, it is regrettable that President Reagan was to discontinue it. For recently the thrust of these has shifted to other issues such as surrogacy and research in the pre-embryo, the human genome, and genetically manipulated organisms, not to mention priorities in allocating scarce resources, as the Oregon senate has recently been engaged in doing. Many countries have set up national bodies to consider such issues and in Britain we await the outcome of proposals for such an organization discussed in April 1990 at a Nuffield Foundation conference. Yet again international comparisons are instructive, an approach that Rothman should be persuaded to adopt in future editions as well as to continue his valuable researches into the present day. □

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