Source Book in Bioethics: a Documentary History

Edited by Albert R Jonsen, Robert M Veatch and LeRoy Walters, Washington DC, Georgetown University Press, 1998, 570 pages, \$95.00, £73.95.

The three editors of this source book have been prominent in the field of bioethics for almost three decades. During this time there have been major developments in medicine which have created numerous ethical dilemmas, many of which have led to legal landmarks and have been the subject of public policy statements. The editors have gathered together a vast collection of legal judgments, public documents and government reports in the following fields in bioethics: experimentation on human subjects; death and terminal illness; organ transplantation; reproduction; child care; genetics, and changes in the nature of health care provision. Most of the material in this text has been previously published and the editors' intention is to provide a comprehensive source book for the student and scholar. It is quite useful to have such a wealth of material in one large volume which would be an asset to a department library.

Albert Jonsen is responsible for editing the first part, which brings together material on the ethical status of research involving human subjects. This includes the Nuremberg Code, the Declaration of Helsinki, documents and reports regarding the protection of human subjects in medical research, research undertaken on minors, in vitro fertilisation and human fetal tissue transplantation.

Robert Veatch, who edits the second part, brings together material which charts changing attitudes towards death and dying and includes selections from the President's Commission on the Definition of Death, which was originally published in 1981, and also selections from the commission's subsequent report on decisions to forego life-sustaining therapy, first published in 1993. Central to both of these reports were the legal and moral debates over Karen Quinlan, Claire Conroy and Nancy Cruzan. These cases became legal landmarks and the relevant documents are included here, together with other material from the

US courts such as the Californian Natural Death Act.

LeRoy Walters edits parts three and four, which cover ethical issues in human genetics and human reproductive technologies respectively. Ethical problems in relation to genetic screening, genetic testing and gene therapy occupy the first collection of documents in part three, and these are followed by excerpts from reports concerning the attempt to map and sequence the human genome. In the following part Walters includes reports on the ethico-legal issues arising out of the new reproductive technologies, such as choices for the infertile, problems arising out of surrogate motherhood arrangements, and the ethical and legal status of embryos and newborns.

The final section is edited by Robert Veatch and it is devoted to the emerging ethical issues in relation to changes in the health care system. In his introductory essay Veatch charts the development of the "rights" perspective in the US and the rejection of Hippocratic paternalism. Material here includes the USA's Anatomical Gift Act, reports from the US Task Force on Organ Transplantation, The President's Commission on Making Health Care Decisions, and related US court rulings on health care decision making.

With the exception of several documents in parts three and four, such as the Warnock Committee's Report on Human Fertilisation and Embryology, and the Glover Commission's Report on the Ethics of the New Reproductive Technologies, the bulk of the material in this collection relates to the American history of bioethics and consequently provides an interesting insight into the attitudes and ethical perspectives which have emerged on that continent during the past thirty or so years.

However, this is a very useful text to have at one's fingertips, especially as many of the documents, published by transient public authorities, are either hard to locate or out of print.

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A New Paradigm For Informed Consent

Irene S Switankowsky, Lanham, University Press of America, 1998, xviii + 135 pages, \$32.00.

Irene Switankowsky rightly recognises that the rhetoric of informed consent can be realised in practice only under certain conditions, conditions which she thinks are currently absent. The stated purpose of her book is to explore these conditions and to help in their realisation. It seeks to do this by gathering together what Switankowsky takes to be all the elements necessary for achieving a fully informed consent. It also seeks to offer practical guidance as to how to recognise when the conditions in question have been met. Does the book do what it claims? In word, no.

For this there are it seems to me two reasons. First, the book is stylistically ill-suited to having any practical impact, and second there is a tension between rhetoric and practice at its own core.

Stylistically, apart from the occasional discussions of cases, of which more below, the book consists largely of uninspiring conceptual unpacking. Perhaps it is a failing of mine, but my understanding of, for example, effective physician-patient communication is not improved by having my attention drawn in the abstract to concepts such as honesty, which are deemed necessary to its realisation. I'm not helped in such cases because I do not so much need to be told such things as to be in some sense reminded of them. And I would be better reminded of them by well-chosen illustrations than by conceptual analysis.

The tension at the core of the book which forms the second reason why it fails in its stated purpose, appears in Switankowsky's consideration of her case material. Switankowsky's rhetoric is clear enough. There is an insistence throughout the book that it is the values, beliefs and attitudes of the patient which should determine medical decisions. Deciding in accordance with these should replace deciding in accordance with paternalistic, sometimes coercive, certainly manipulative, physician attitudes. When these are replaced, Switankowsky says, then the "autonomy enhancing model" of consent will become a reality, instead of the historically dominant "harvest avoidance" model. In the former, but not in the latter, there is genuine informed consent.

This is the rhetoric, but it is not realised in Switankowsky's case discussions. According to Switankowsky a necessary condition of informed autonomous consent is rationality. Bearing that in mind, here is one case Switankowsky considers.

A patient has heavy and long menstrual cycles. The problem is eventually diagnosed as fibroids. After some time trying depo-provera, she becomes severely anaemic and is admitted to a hospital emergency ward. The doctors agree on the need for a partial hysterectomy. Nevertheless, there is a chemical option, which aims to shrink the fibroids, and which in all honesty the doctors must explain to the patient. This treatment has serious side effects, and the fibroids may still return. Switankowsky asks us to imagine two women reflecting upon these choices. Woman A chooses the surgery, Woman B chooses the medication. Which, asks Switankowsky, chooses rationally, and hence can genuinely consent?

For Switankowsky the correct answer is Woman A. A recognises that partial hysterectomy is the medically rational thing to do; she does not let other issues cloud her judgment. Woman B, however, chooses the chemical treatment. She is worried about her femininity, and is quite unreasonably swayed by the recent death of a close relative on the operating table. Switankowsky comments that if B just stepped back for a moment, she would see that, at 37, she shouldn't try to have more children, and that the minuscule chances of dying under anaesthetic should have no bearing upon her decision. B is irrational, she cannot genuinely choose the chemical option.

What seems to lead to the conclusion that B is irrational is Switankowsky's inability to see that anything other than medical matters could be relevant in such cases. Whatever is medically indicated must be the rational choice. One is tempted to respond, perhaps, that B's values are different from A's. That for B, but not for A, femininity does matter. Switankowsky seems committed to saying either that such matters are irrelevant, or that B does not know her own values or does not know them deeply or adequately, or that she has the wrong values. It appears that in Switankowsky's treatment of this case, medical paternalism, having apparently been shown the front door, has walked boldly in again at the back. Decisions must conform to the patient's values; but on pain of incompetence, the patient's values must be medical values.

Switankowsky does have a response, but it seems to be purely verbal in character. Within the "autonomy en-

hancing model", the physician cannot persuade, coerce, manipulate, or decide for a patient, however irrational. But she can, and should, guide the patient. This central notion of "guidance" is not indexed, but seems to consist of getting the patient to look again at her decision, helping her to "stand back" and realise she has been irrational. That the appeal to guidance is a merely verbal manoeuvre appears if we imagine the doctors guiding B. Since, according to Switankowsky, it is in part the content (as opposed to the process) of B's decision which is the problem, we can judge that she has been guided only when she changes her decision to the one her surgeon considers rational. Medical paternalism is dead; long live medical paternalism.

Switankowsky's treatment of cases is in tension with the rhetoric of the "autonomy enhancing model" of informed consent she proposes. Her book, far from achieving its avowed purpose, tends to reproduce the gap between the rhetoric and the practice of informed consent which it purports to bridge.

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Who Goes First? The Story of Self-experimentation in Medicine

Lawrence K Altman, California, University of California Press, 1998, 430 pages, \$17.95.

This is the paperback edition of a book that was first published in 1987. In his preface, the author stresses that in the USA the issue of self-experimentation and the choice of the first human volunteer has not been seriously addressed. He goes on: "This dearth of attention reflects medicine's apathy towards its own history which is rich in fascinating and instructive stories about self-experimentation". Altman is clearly fascinated by this topic and has studied it for 30 years. The book, which is well researched and informative, is written for the general public, but will also be of interest to medical students and doctors with an interest in medical history.

Faced with a deadline and not wishing to spoil a good read, I have based my comments on the first eight of 15

chapters, and the final chapter. As yet unexplored are chapters on dietary deprivations; lifetimes of self-experimenting; the red cell riddle; cancer; "black and blue at the flick of a finger", and choosing the right animal. Altman, a clinical associate professor of medicine, is also medical correspondent of the *New York Times*, and uses alluring chapter headings.

Six chapters are devoted to various infectious diseases. They describe topics as varied as early attempts to develop vaccines, and the discovery that mosquitoes are the vector for yellow fever. Altman is at some pains to demonstrate that Dr Walter Reed who was credited with this discovery, played a less than noble part in the work. Having persuaded his colleagues to self-experiment, he removed himself from the scene with alacrity, leaving them to risk their lives. One, Dr Carroll, contracted yellow fever but survived. Another, Dr Lazear, died, attended by Professor William Osler in 1900. This book brings medical history alive!

In a chapter on parasitic diseases we are told that 97% of world finance for biomedical research is spent on health problems in developed countries. A note at the back of the book mentions that parasitic diseases are largely responsible for the 30-year difference in life expectancy between people in developed and underdeveloped countries. A point such as this deserves mention in the main text, and some ethical exploration.

I found the arrangement of the book slightly irritating. A prologue of 13 pages precedes the main text (303 pages), which is followed by 100 pages of notes. Much of interest is written in the notes, but reading them in context involves endless to-ing and fro-ing.

Not being a medical historian, much of the information was new to me, and much was fascinating. I empathised with Werner Fossman, a young German doctor, who was excited by the possibility of placing a catheter in the human heart. He showed pictures from a veterinary text to his consultant, who forbade him to try the technique on himself. He went ahead in secret, and in 1929, threaded a catheter through the brachial vein into his right atrium, then walked down to the basement to get a horrified technician to take an X-ray, which proved the point. Later he pioneered angiocardiology on himself. His work, though unrecognised at the time, later won him a Nobel prize. His career was disrupted by the