

# PostScript

## BOOK REVIEWS

### Gene Technology and Social Acceptance

W P Von Wartburg, J Liew. University Press of America Inc, 1999, US\$41.50, pp 338. ISBN 076181325X

Over the past 15 years, since the publication of Walter Bodmer's report for the Royal Society, the public understanding of science (PUS) has become a positive industry in the UK. Initially intended by the natural scientists to foster public acceptance of science, it has gradually drawn on a longer and deeper academic tradition in Britain of the social studies of science. Some of that social science research predicted the recent "moral panic" over genetically modified (GM) crops and food, but both natural scientists and governments have held social science in low esteem for many years, so it went unremarked at the time.

The hypothesis of those who launched PUS was that the public was merely deficient in factual knowledge and that public acceptance of science could be improved simply by setting out "the facts". Social studies of science had demonstrated the vacuity of this "deficit model", both theoretically and empirically, long before the GM furore provided an experimental falsification of the hypothesis that was clear to all. With the publication of a seminal House of Lords report on science and society in 2000, a more socially informed way of thinking is now entering the British mainstream.

This book offers a view from a rather different perspective: it is neither British nor a work of social scientists, but comes from the head of corporate communications for Novartis (who also acts as professor of health policy at a Swiss graduate school) and from the communications manager of a major German chemical company. As one might expect from a continental European perspective, there is a lively awareness of social factors in the acceptance of new technology, but sadly the conceptual framework within which these authors work appears dated and unrealistic.

It is an abuse of language (and of the conceptual clarity that should underlie the use of language) to divide, as these authors do, public reaction to GM technology into "rational" and "emotional" categories. Although the authors try to limit the damage by noting that the emotional factors are not "any less valid, less legitimate, or less important", it follows immediately that the "emotional" factors are irrational. Nor does it help that their subheadings under "rational factors" include: medical benefits; economic benefits; environmental benefits; and social benefits [my emphasis]; whereas the "emotional factors" include: concern about safety and aversion to risk. This is not classification but rhetoric.

In premodern (peasant) societies, almost all risks are natural disasters, Acts of God, such as crop failure; famine; flooding; pestilence, and devastating weather. In contrast, in a modern society risks almost all result from social choices of technology—whether: to build

a nuclear power plant or to burn coal; to slaughter a nation's cattle herds or hope that BSE will not transmit to humans, to plant GM crops. Although we accept socially imposed technological risks—indeed it would be impossible to function in modern society if we did not—that acceptance is provisional and will turn to rejection if anything goes wrong. The character of risk changes from premodern to modern society: one does not sue God for a natural disaster, but we believe it justifiable to sue if a train crashes, or an aeroplane falls from the sky.

Socially imposed technological risks are a central, defining element of life in modern society, not a secondary "emotional" factor. Strangely, although the fundamental text that sets out this thesis on risk—*The Risk Society*—was originally published in German by a German sociologist, Ulrich Beck, it appears not to be cited in this book. (It has been elaborated in the UK by Anthony Giddens, now director of the London School of Economics, but he appears not to be cited either.)

Despite its flaws, there is a great deal in this book. It attempts a "big picture" overview, and much of its factual and historical content is interesting and valuable. The authors provide a clear exposition of the technical aspects of biotechnology itself and do appreciate many of the social and ethical issues that it raises. It seems to represent a genuine attempt to reach out from the laager of technological supremacists to the wider community to seek consultation and consensus. As such it is to be welcomed, for no purpose is to be served by repeating, with genetic modification, the mistakes of nuclear power. But for all that, this book also shows just how far there is for the scientific-industrial community still to go before it fully appreciates the rational foundations for the public to assert its voice, its values, and its expertise, as well as, and against, the well-articulated voice, values, and expertise of the biotechnology companies.

T Wilkie

### Medical Ethics: Sources of Catholic Teaching

Edited by K O'Rourke, P Boyle. Georgetown University Press, 1999, £26.95, pp 442. ISBN 0878407227

This third edition of O'Rourke and Boyle's *Medical Ethics: Sources of Catholic Teaching* is a useful and comprehensive collection of statements published, for the most part, by the central authorities of the Roman Catholic Church, the National Conference of Catholic Bishops in the United States and the bishops' conferences of individual US states on a wide range of issues in the area of medical ethics. The statements are arranged alphabetically according to subject matter. It is useful to have such a wide range of documents available in one volume, many of which would otherwise be accessible only with difficulty. The documents included range from major encyclical letters issued by more recent popes on matters such as human sexuality (*Humanae Vitae* by Paul VI) and human life (*Evangelium Vitae* by John Paul II) to ad hoc responses by

individual bishops to very particular questions with which they have been faced, and upon which they have felt the need to offer some guidance. Unfortunately no guidance is provided as to the weight and authority that is to be given to the various documents. For example, a major philosophical and theological treatise such as the encyclical letter, *Evangelium Vitae*, by John Paul II is presented alongside an ad hoc response from the bishops' conference of an individual state to a particular question that has arisen, as though they were of equal significance and importance. This detracts seriously from the usefulness of the collection and gives a misleading weight and authority to a great many of the statements gathered together here.

The impression could also be given that documents such as these provide the only, or indeed the major, source for Catholic reflection in the area of medical ethics, whereas of far greater significance and abiding value are the contributions to this field of medical ethics of authors such as the late Richard McCormick, John Paris, and Albert Jonsen, to name but a few of the more prominent.

M O'Dowd

### The Ethics of Clinical Research in Developing Countries

Nuffield Council on Bioethics. Nuffield Council on Bioethics, 1999, free, pp 24. ISBN 0952270153

The discussion paper produced and published by the Nuffield Council on Bioethics about the ethics of clinical research in developing countries is a timely, useful and (for such a concise publication) comprehensive document. It will prove useful for those planning research in developing countries, as well as for those already working in the developing world and planning research. The sponsors of research should also read the paper, whether they are pharmaceutical companies or a host country's statutory bodies, reviewing research proposals.

The topic has most recently been discussed in the context of the controversy surrounding trials of zidovudine (AZT), but the authors rightly point to a much wider agenda. They also convincingly highlight the differences and difficulties that are particular to research by developed countries in developing countries (rather than those inherent in all research). They also touch, however, on the issue of self generated research in the developing world.

Perhaps the general issue can most easily be summarised in terms of the competing arguments for universality in the ethics covering research (which can be seen as arrogant paternalism from the developed world), and for acknowledging the need for local self determination (which can be seen as condoning unethical behaviour). Taken to the extreme the "Universal School" may result in no potentially useful research being done in the developed world because of the fear of any harm. The local self determination group can, however, fall into the dangers inherent in having varying standards and therefore lead

to the developing world being exploited by the richer and more powerful North.

More broadly, it is possible to see this branch of ethics as a subset of the overall ethics associated with development, underdevelopment and poverty. Many of the special dilemmas of consent and of appropriate standards of care arise directly from poverty and inequality. For example, those who argue for developed world standards of care for all trial participants, will need to ask if this *medical* care should continue to be provided, even when the underlying cause of the condition is malnutrition. Should one then provide developed world standards of food, then hygiene, then infrastructure and so on?

The paper covers the existing guidance and the dilemmas, contradictions, and problems they pose in their application. It also covers the issues of non-therapeutic research, consent and concern for those who remain after a trial is over.

Not surprisingly in such a paper, there are more questions than answers. The authors do, however, point to one very good example of practical assistance that the guidelines can provide. This is where pro-active guidance (unfortunately provisional and therefore un-referenced) is being provided in the form of a document on ethical considerations in international trials of HIV preventive vaccines by the Joint United Nations Programme on HIV/AIDS (UNAIDS). Perhaps the future lies in the production of appropriate intermediate guidance and training, in a minimum set of ethical issues and practical considerations that should be addressed before research is started. This may enable a compromise to be reached between some of the impracticalities and difficulties in applying developed world standards and developing universal standards. This paper is a very useful start in identifying the issues and indicating a way forward.

A P Bacon

### The Ethics of Health Care Rationing: Principles and Practices

J Butler. Cassell, 1999, £16.99, pp 248. ISBN 0304705829

This book is about scarcity and rationing in health care and the ethical questions they raise. It is based on the premise that if the aim of a responsible government is to balance the nation's varied claims upon the collective purse, then no government can be morally blamed for failing to remove the need of rationing from the National Health Service (NHS), and thus rationing as such cannot give rise to legitimate moral concerns. The question that needs to be addressed therefore is not whether rationing itself is unethical, or even whether any particular distribution mechanisms are unethical, but whether they are structured and work in morally acceptable ways, and lead to morally acceptable results.

In the first chapter Butler describes the gap between needs and resources. He describes what has been done (mainly) in the UK as a way of providing the background to the rationing debate. The second chapter addresses the moral basis of rationing by focusing on which personal qualities we are prepared to accept as a fair basis for discriminating between individual patients. The author could not have chosen a simpler and yet more effective example to drive us through the debate.

Chapters 3 to 5 tackle the debate on rationing from a different point of view. Here Butler explores the moral issues of fairness and justice through the structures, processes, and outcomes of health care. Given that health services will always be in short supply in relation to potential demand, he asks whether they are structured and organised in ways that will promote people's fair and equitable access to health care. This question is addressed by taking the reader through three competing theories of justice: those of Rawls (social justice), Daniels (fair equality and opportunity), and Doyal (human need). All three share a common feature in highlighting that the structure and organisation of health care cannot be left to chance or interest but must be planned and implemented in ways that make explicit the principle of justice they are seeking to achieve.

Butler then takes the reader through the various processes of health care. Starting with a description of Waele's theory of responsible or responsive government, he presents numerous arguments about, and examples of, implicit and explicit rationing, public involvement in, and political and professional accountability for, rationing decisions, pointing out the potential conflicts between different moral concerns at different levels. Clinicians have a primary obligation to treat the individual patients before them, managers to see that public resources are not wasted, and politicians to use the nation's resources fairly and to balance interests and expectations of different sections of society. Within a given budget constraint, are government and health authority decisions made on the basis of defensible ethical principles? Given that doctors and nurses are unable to do all they would like to do for their patients, are they making choices based on established ethical criteria?

Chapter 5 addresses the ethical issues of health care rationing and health outcomes. As Butler states, outcomes are elusive things. Even at the patient level measuring improvements in health may be tricky, but at population level, where ethical questions are more likely to be posed, the difficulties multiply. Moreover, improvements in health are likely to reflect a variety of social, economic, environmental, educational, and occupational changes among which delivery of care is only one. In situations where all objectives cannot be achieved and comparisons between different outcomes have to be made, how can we fairly establish that some objectives are morally to be preferred to others? Should outcomes be perceived in terms of meeting individual need, the maximisation of total health gain (utilitarianism for example, using quality adjusted life years) or as the narrowing of the health gap between rich and poor?

Chapter 6 singles out this book from others on the topic. This chapter contains a series of stories the author has gathered from professionals who deliver health care. In order to present an unbiased selection of stories, Butler's includes anecdotes from doctors, clinicians, nurses, and managers. Despite their differences, each story contains a common thread in that although none say so openly, each clearly describes a decision which implies rationing. These stories clearly bring out the conflict between moral concerns at the different levels.

From a professional point of view this book has much to offer both to those familiar with the subject and to those new to it. Moreover, although the book is mainly concerned with the UK what it has to say can apply equally to

other countries, particularly other countries in Europe. Overall this book is comprehensive, thought-provoking, readable, and highly recommended.

M Longo

### Speaking for the Dead: Cadavers in Biology and Medicine

D G Jones. Ashgate, 2000, £50, pp 304. ISBN 1754620735

This book is well-timed. Jones has produced a broad-ranging work focused on a novel subject: the cadaver. In this year alone, high-profile media issues have included the non-consensual storage of postmortem examination tissues at Alder Hey; the trial of Dr Heinrich Gross, for killing and storing the brains of children in Austria in the second world war; debate about the medical uses of fetal tissues, and the repatriation and reburial of indigenous remains from museums.

*Speaking for the Dead* is underpinned by a profound respect for cadavers. Jones makes the claim that respect accorded to persons (and their wishes) extends to their tissues after death. He bases this on both utilitarian and Kantian grounds. Hypothetical arguments—such as that of the “neomort”—flesh out the argument.

Historical examination of attitudes to cadavers provides a context for this work. It is brave and noteworthy to describe explicitly our fearful subjective response to dead bodies. I would unreservedly recommend this chapter alone to medical students commencing dissection. It is a humanising explanation of the heritage and necessity of undertaking post-mortem examination and of learning anatomy by dissection.

Jones then advances another strong contention: that the use of unethical research data and results constitutes moral complicity. He discusses contentious research derived from autopsies and war-time experiments, as well as touching on legal issues such as whether the body and its parts can be regarded as property.

The response to indigenous concerns about archaeological findings is powerful. Jones manages to balance, on the one hand, strong arguments for advancing knowledge in science and anthropology, and on the other, the interests of indigenous peoples in respecting ancestors.

The discussion of organ transplantation policies and the incipient ethical dilemmas of new technologies is generally solid, but occasionally fails to accommodate the full range of opinions. Given the broad remit of the field, Jones does well to cover the many hypothetical situations which may be expected.

In discussing brain death, *Speaking for the Dead* reintroduces the perspective of the cadaver, the person he or she was previously, and other stakeholders. These viewpoints, in defining brain death, frequently become subsidiary to technical neurophysiology and philosophical argument about personhood, selfhood and consciousness. Jones makes more action guiding points, and thus his discussion is more clinically relevant than most other debates about brain death.

Finally, Jones expounds on his particular expertise, embryology, and specifically addresses brain birth. His arguments are based upon careful study and are highly pertinent. I hope they will be heeded.

*Speaking for the Dead* ranges far more widely than its title would suggest. Gareth Jones has covered a neglected area thoroughly. Moreover, he has integrated myriad tangential ethical problems into his discussion. Ramifications for the fields of research ethics, medical education, anthropology and policy are significant. Questions raised for the future are numerous, and Jones provides a compelling, well argued and consistent framework from which to address these problems. I would recommend this book to a broad audience—laypersons, doctors and philosophers—for its simplicity, eloquence and viewpoint. It is a thought provoking work, and engrossing to read.

D Sullivan

## The American Medical Ethics Revolution

Edited by R B Baker, A L Caplan, L L Emanuel, *et al.* The Johns Hopkins University Press, 1999, US\$59.95, pp 396. ISBN 0801861705

Codified moral medicine is an antidote to many problems, a bulwark against wallowing in the morass of moral idolatry, and a rampart that should be strengthened continually, rather than dismantled. The notion of medical professional self regulation, by means of codification and collaboration, was actually conceived in Britain, by Dr Thomas Percival, but born in America. *The American Medical Ethics Revolution*, through the medium of a tetrad of editors and a stellar collection of luminaries, displays the pedigree of codified American medical ethical thought back to its earliest progenitor: the primordial 1847 American Medical Association (AMA) code of ethics. The clash of deftly handled academic sabres vivifies the medical ethical dimension of the practice of medicine in America, and reveals the sharp contentiousness underlying American medical ethics, as well as the acute timeliness of the volume.

The rich blend of varied viewpoints culled by the editors was delivered, originally, as papers at a conference in Philadelphia, PA, in March 1997, intended to commemorate the founding of the AMA, and to celebrate the sesquicentennial of its pristine code of ethics. The ensuing volume ramifies into branches of good writing and philosophic musings appertaining to American medical ethics, reaching from the far past to the uncertain future. The volume is comprised of 20 chapters and includes notable appendices, showing the evolution of AMA principles and codes of ethics, from 1847 to 1997. The thoughtful ruminations on the evolution of American medical ethics reflect the crisp thinking of noted scholars drawn from diverse fields, including: ethics, law, public policy, philosophy, medical history, and sociology.

The AMA code of ethics has a history of dissonance, albeit of continued vitality. The lineaments of the code have shown the ability to evolve, in response to professional and larger societal pressures. Although today, in America, medical ethical issues are possibly more beguiling than ever, some may opine that the code is really an anachronism which offers a mere patina of relevancy, and really nothing in the way of enforceability. Rigorous debate about its continuing vitality and relevance is certainly a very healthy exercise. And, it is in the realm of stirring, informed debate and discussion that the volume particularly excels.

Three chapters, for example, proffer a thought-provoking, trichotomy of views concerning the singular question: who should control the scope and nature of medical ethics? Several chapters examine the relevance and adequacy of the traditional paradigm of codified, collaborative medical ethics in the context of particular, contemporary challenges to American medical ethics, relating, for instance, to “alternative medicine”, managed care, population health, and the challenge of providing universal access to health care, given limited resources.

The lengthy time continuum of the volume encompasses forward-looking comments on future challenges to traditional medical ethics, involving, for example, molecular medicine. Given the uncertain role of ethics in the unfolding genetics revolution, it cannot be gainsaid that it is timely and potentially salutary, to ponder, in an informed intellectual sense, whether codified ethics can favourably help guide the future of biomedicine.

The recondite nature of this volume is well tailored to suit the curiosity of academically inclined readers, interested in medical ethics in America. Its abstruseness, however, is ill tailored to fit the lay reader; and may even fall outside the ken of comfort of some clinicians. In this respect, the volume is ineffectual as an educational conduit for the possible linkage of professional ethics with broader societal ethics.

Withal, the volume indubitably is a beacon of superb scholarship, illumining the path to moral rectitude, and barriers along the way, for academicians.

L Uzych

## Gene Therapy and Ethics

Edited by A Nordgren. Acta Universitatis Upsaliensis, 1999, 208 SEK, pp 175. ISBN 915544640X

Gene therapy research and its clinical application raise a large number of ethical, legal, and social questions. Many of these are discussed in Nordgren's anthology. The contributions come from a number of different disciplines, including bioethics, genetics, social science, and theology. The book is divided into five main sections (following a short introduction): scientific aspects of gene therapy; the history of, and prospects for, gene therapy; conceptual issues; gene therapy in a German and Japanese context, and a section on the uses of gene therapy in relation to, for example, testing and screening. The contributions are quite diverse and mostly well worth reading. From the perspective of medical ethics the contributions by LeRoy Walters, Eric Juengst, Karen Lebacqz, Nikolaus Knoepffler, and Christian Munthe are of particular interest.

Walters's contribution focuses in part on the issue of eugenics. He defends a voluntary germ-line gene therapy programme as a means of reducing the transmission of genetic diseases to future generations. In the context thereof he points to differences, in terms of targeted diseases or deviations, between past eugenic programmes and the sort of germ-line genetic intervention programmes that would probably be run today. Walters also discusses the difference between gene therapy and genetic enhancement. He thinks the distinction is vague. Eric Juengst undertakes the task of clarifying the distinction, discussing three accounts of it. These appeal to the goals of medicine, the notion of species-typical

functioning and particular concepts of disease, respectively. Juengst argues persuasively that none of these distinctions bear moral weight. For instance, he points out that there are cases of medical treatment leading to above-species-typical functioning that seem obviously morally desirable (for example the use of gene therapy to empower the immune system to eliminate cancer cells). Juengst, however, is not uncritical of genetic enhancement; and there are some affinities between his concern that genetic enhancement should not involve complicity with unjust social biases and Lebacqz's views.

Lebacqz argues that the concept of therapy presupposes a distinction between normal and abnormal. How that distinction is drawn often depends on power structures in society and, hence, is not necessarily based on whether being unusual in some particular respect makes one worse off. Accordingly, gene therapy which targets perceived abnormalities, such as dwarfism, may not benefit anyone. It may simply make people more alike. Lebacqz suggests that if disability is a wholly social construct, it is society and its reactions to people who differ from the “genetic norm” that needs to be changed, not the differing individuals. It is not clear why this should be thought to follow. In our society inability to read is, let us suppose, a socially constructed disability. Suppose we could make everyone read using moderate resources, and that a society in which inability to read was not a disability would be in many respects much worse than ours. Why should we prefer, morally speaking, the latter option? The more general point is that it is unclear why, from the point of view of justice, a society in which people are different in various respects would be preferable to a society in which each of us is well off to the same extent but there is less human heterogeneity.

In his contribution, Nikolaus Knoepffler embraces the Kantian idea of human dignity and treats it as the fundamental principle of bioethics. Roughly, in his view this idea implies that, whereas somatic gene therapy is morally unproblematic, germ-line gene therapy and germ-line enhancement are morally unacceptable. Knoepffler does not explain why, exactly, this follows. At one point he seems to suggest that the fact that we have no common grounds for determining which enhancements are desirable implies that enhancement violates the Kantian principle, but such irresolvable disagreements simply seem beside the point.

In an interesting article, Christian Munthe convincingly argues that there is no morally relevant difference between genetic interventions involving the treatment of a particular individual and genetic interventions involving the exchange of one possible future person for another. Examples of the latter sort of intervention include the preselection of embryos based on preimplantation genetic diagnosis.

K Lippert-Rasmussen

## Creating Accepting Communities

S Dunn. MIND (National Association for Mental Health), 1999, £9.99 (£1 p+p), pp 181. ISBN 1874690871

The government's social exclusion unit (SEU) was established to help individuals, groups, and regions overcome deprivation and discrimination resulting from a combination of problems, including unemployment, poor

quality housing, low income, lack of education/training opportunities, bad health, and family breakdown. Such difficulties are commonly experienced by people with mental health problems who also have to cope in a society which alienates and rejects them, barring them from every aspect of community life. Remarkably, even the SEU's remit excludes consideration of the obstacles to social inclusion faced by those with a psychiatric diagnosis.

*Creating Accepting Communities* is the final report of an inquiry commissioned by MIND, which looked at the nature and extent of social exclusion experienced by people who use mental health services in Britain. The inquiry panel received written and oral evidence from a wide range of individuals and organisations, including mental health practitioners, high street retailers, groups working within the voluntary sector, and, importantly, service users.

The book is clearly written and the material well organised into four main chapters, each of which ends with a useful summary of the key issues raised. Quotations from witnesses are used extensively throughout the narrative, giving real meaning to the findings, and to participants a sense of "ownership" in the report.

The first chapter summarises evidence presented to the inquiry on how a psychiatric diagnosis can exclude people from a range of socially significant areas such as employment, education and training, aspects of daily life (that is, access to goods and services, social networks, etc), and empowerment within mental health services. The panel found widespread evidence of social exclusion and dismissed claims that this was simply the result of poverty. Instead, they argue that while policy initiatives should focus on addressing the poor material circumstances of service users, they should also work towards creating greater social cohesion or social inclusion.

A range of ethical aspects associated with social inclusion is briefly but coherently discussed in chapter 2. In particular, inquiry evidence is used to evaluate the relationship between individuals and their wider community, and to address the following questions: how does society judge the value of a person? How does society differentiate individual "badness" from "mental illness"? How should risk be defined? What is meant by the participation and empowerment of service users? Essentially, the findings support the basic need to recognise the absolute value of individuals and to acknowledge that any ethical approach to social inclusion needs to balance this against existing social forces: differences can only be resolved through the participation of everyone involved.

Chapter 3 discusses a range of initiatives that have been set up to promote social inclusion within the key areas of work, education, the arts and the media, daily living, and the mental health services. The panel highlighted three areas where more work should be done to improve social inclusion: the development of more local initiatives based on inter-agency cooperation, legal and policy-based reforms at national level and the promotion of more intensive public education programmes on mental health. Based on this inquiry evidence, chapter 4 presents a series of recommendations aimed at directing social progress "from exclusion to cohesion".

In general, the report raises the profile of a wide range of issues concerning social exclusion and provides an informative overview of

current policy and practice initiatives. Unfortunately, because the book's remit is so wide, its depth of analysis is compromised, leaving unchallenged some very difficult ethical barriers to social inclusion.

For example, little is currently known about the nature of day-to-day interactions between "them and us" and the consequences of these interactions for the promotion of a society based on "inclusive diversity", particularly in the face of: 1) growing public demands for more zero tolerance initiatives; 2) the threat of new legislation designed to exclude those with a serious personality disorder, those who fail to comply with medication while living in the community, and those who are disruptive in schools; 3) media campaigns provoking street demonstrations against groups the media feels society should no longer tolerate, and 4) employment practices which measure individual value in terms of productivity to the point whereby even mental health services lack confidence in service users' abilities.

Ultimately, the problem of analytical depth is a methodological one that requires the development and integration of research initiatives at both the micro and macro levels of social inquiry. Moreover, these observations should not detract from what is an excellent report and an important reference point for anyone interested in promoting the social inclusion of people who experience mental ill health.

A Colombo

### Priority Setting and the Public

P Mullen, P Spurgeon. Radcliffe Medical Press, 2000, £24.50, pp 168. ISBN 185775297X

As its title suggests this book's main area of inquiry is the rationale for, and methodology of, public involvement in priority setting. Mullen and Spurgeon set out to evaluate a number of assumptions and hard issues in priority setting. In doing so they have produced a volume that is both a useful introduction to this area and a worthy piece of research on an important theme.

They begin by contextualising the debate about prioritisation within the recent history of health system reform in the UK and other nations. This move enables them to give an analysis of considerable scope. They are not just interested in rationing and public involvement but also in questions about the level to which the UK National Health Service (NHS) ought to be publicly funded. Given the frequently stated assumption that rationing is inevitable it is very refreshing to read a book that grapples with the difficult, more primary question of whether rationing itself is in fact necessary.

They note that reform processes and initiatives in the health system have served to focus attention on the need for priority setting but that there is a need to evaluate carefully the basis of this need. The present level of funding that the NHS receives is a matter of choice and not simply a result of economic necessity, as is frequently implied. They suggest that we should think carefully about the inevitability of rationing and our inability to pay and instead work out how to provide treatments that are of undisputed efficacy.

In chapter three they examine the basis for public involvement in priority setting. Given that many would think that public involvement in the setting of priorities is a good thing they ask the pertinent question, whether such

involvement would result in the optimum set of priorities and consider whether it may risk a "dictatorship of the uninformed" (page 34). Other key difficulties addressed are the problems of finding a group that can be considered representative.

In chapter four they survey the traditional approaches to priority setting. This includes a detailed section on QALYs and the standard objections to them. This chapter contains an interesting section on how the rule of rescue can conflict with the maximisation of health care gain that is associated with QALYs (pages 44-45). They cite the Jaymee Bowen case as an example of the depth of feeling that can be evoked when the rule of rescue conflicts with the maximisation of health care benefit.

Their sixth chapter considers in some depth empirical methods that can be used to elicit the values of the public about priority setting. They present a broad range of possible methods in a way that makes them useful, not only for ascertaining views about prioritisation but also for gaining information about other empirical questions within medical ethics.

Given the amount of literature on this topic it is inevitable that some issues are dealt with in a fairly summary fashion, but when they do this the authors make reference to the wider literature.

All those interested in prioritisation and the NHS ought to read this book. It's likely to be of special interest to those making prioritisation decisions at all levels.

J McMillan

### Catholic Ethicists on HIV/Aids Prevention

Edited by J F Keenan SJ. Continuum, 2000, US\$24.95, pp 351. ISBN 0826412300

This impressive and informative book deserves a wider readership than it is likely to get. Unfortunately there are still too many people who consider they have no need to read anything about the virus as it will, to their way of thinking, never touch them. In addition there will be those who think that a volume by Catholic ethicists will be too narrow in outlook to be worthwhile. Both sets of people are mistaken: HIV is here to stay, there is no cure nor is there likely to be and sooner or later it will affect, let alone infect, millions across the world. On the second count readers will be surprised and energised by the clear and honest debate concerning the teachings of the Catholic Church.

The first and longest section is made up of a series of case studies ranging from needle exchange in Puerto Rico, to confronting social stigma in Uganda, and matters relating to confidentiality in Australia. The second consists of seven chapters covering fundamental moral issues for HIV prevention; the chapter by Lisa Cahill (Boston, USA) on AIDS, justice and the common good and the one by Paulinus Odozor (Attakuru, Nigeria) on Casuistry and AIDS, are particularly worthwhile. Kevin Kelly (Liverpool, UK) provides the conclusion. Readers would do well to get hold of his book, *New Directions in Sexual Ethics*, (Geoffrey Chapman, 1998) in which he highlights what is undoubtedly of paramount concern in developing countries namely poverty, the subjugation of women and related gender issues.

The most obvious moral issues are those surrounding the use of condoms but they are not the only ones. What if an infected person refuses to tell his or her partner of their status: is any duty incumbent on the doctor treating

the positive person to inform the partner? Where does confidentiality begin and end? One of the saddest cases, and not as rare as it may seem, is of a married couple in Italy, both infected, who want to have a child. Will the child also be seropositive? Will one or both parents live long enough to look after the child? Who else should know of the situation?

The Catholic Church has always had high ideals even if many of its adherents, including some in positions of power and authority, have not lived up to them. Those ideals cover not just areas of chastity and fidelity but also those of charity and truth where each one of us has to strive constantly to live up to a more responsible way of living. The church has particularly strong teaching on fidelity in marriage and against premarital and extramarital sex. It is important to recognise the connection between this strong teaching and the basic values of family life and the worth of the individual, on the one hand and, on the other, the abuses that arise from pressures on innocent girls and women, particularly in some cultures. A universal approval of condom use would lead to even greater ills and abuses; how can we work towards the time when married couples have sufficient education and knowledge to work out for themselves the right use of conscience with regard to their sexual activity? Inevitably there are occasions when a solution is far from obvious: we have to remind ourselves frequently that we are fallible human beings with free will. This book goes a long way towards enabling the reader to consider and ponder at some considerable depth, a variety of dilemmas and questions.

In so many countries, including our own, a conspiracy of silence, of denial, has grown up in the face of HIV and AIDS. It is only when HIV is looked at objectively and dispassionately, regardless of the moral stigma that so often haunts those affected by the virus, that the real work of prevention will occur. Education is essential. Only when we understand what the virus is, how it is passed on, what it does to individuals and to families—not least the children—will the global epidemic begin to be contained. Just to know that on average 5,500 funerals take place each day in Africa as a result of HIV should go a long way towards impressing upon us what the consequences in terms of personal tragedy and economic structures are in that continent alone. The rapid spread of the virus in India, passed off as “a bad illness”, resulting from infidelity and prostitution, as well as from untreated blood products, gives cause for alarm. “It won’t happen to me” remains an all too common remark, betraying a total lack of awareness of just how many people are now suffering from this virus, either in themselves or in those they love. This book should be widely read and used for discussion and reflection on just how far each of us has a responsibility for others in this desperately needy world. In our multicultural medical practices all doctors need to be more aware of HIV and its consequences.

**D Bell**

### **From Chance to Choice: Genetics and Justice**

A Buchanan, D W Brock, N Daniels, *et al.* Cambridge University Press, 2000, £17.95, \$US29.95, pp 398. ISBN 0521660017

With over 10 000 bases of DNA being sequenced around the world per minute, it is vital that ethical discussion continues to keep pace with genetic research. This contribution

by four top theorists in bioethics carefully considers the implications of the many ways genetic information will influence human health and reproduction, by considering “the most basic moral principles that would guide public policy and individual choice concerning the use of genetic interventions in a just and humane society” (pages 4–5).

Proceeding with the themes of rights, justice, and harm, problems addressed by the authors include: the significance of the moral difference between treating genetic disease and altering personality characteristics; whether the utilisation of prenatal interventions to avoid disability discriminates against the disabled, and who should have control over the utilisation of this technology.

The main focus of the work is upon the future of genetics, however this is framed within an “ethical autopsy” of eugenics, in which the inappropriateness of past practices is considered. It is argued that the wrongs of eugenics (broadly, a denial of freedom) must be recognised when considering what an ethical practice should now constitute, but that wanting to provide future generations with genes that could contribute to their lives going better is not necessarily unpalatable. It is vital, however, that any such procedures are pursued justly.

After moving through several topical themes in genetics (which are highlighted in the introduction by the presentation of several futuristic genetics scenarios, the final chapter of the book draws out the major principles that should be used in policy-making about genetic technology.

Among the arguments advanced throughout are claims that a “normal functioning” perspective for the distribution of genetic technology is acceptable, and that this may also theoretically be applied to non-therapeutic interventions. Yet preferable to this is for social institutions to be designed which do not exclude people who are worse-off, and for plurality in views of personal assets and the good life to be protected (chapters three and seven). In chapters four and five it is argued that the boundary between treatment and enhancement does not always coincide with what is acceptable and unacceptable, however, it is a good starting point for what the obligations of the state should be in delivering health care. The authors found no “reason to object in general to using genetic influences any more than environmental ones” (page 202), however concerns about both fairness in the distribution of this technology and medical risk should still be recognised. Chapter six explores in more detail the idea of reproductive freedom in preventing or allowing harm to children, and discusses ways around the “non-identity” problem to illustrate a basis for obligations to prevent harm. Another effect of this obligation, however, is that parents should strive to benefit their children, and the limits of a requirement for these benefits are addressed in chapter seven, through an analysis of several disability-rights critiques of genetics.

This is an excellent book that immediately engages the reader. Among the strengths of the analysis is the use of real-world examples, a recognition that there may be more than one ethical solution to each problem in genetics, and an articulation of the limits of ethical theory. Although each author has contributed different chapters, the book does not suffer from an inconsistency of style. It is worthwhile to read it from beginning to end, as subtle connections between many apparently unrelated issues begin to emerge. It will, how-

ever, also be useful as a tool for anyone interested in obtaining clear analysis of topical issues in genetics. An extremely comprehensive table of contents also makes the book easy to navigate.

Overall, this book provides new insights on many important questions in genetics, but it also elegantly illustrates the inherent complexity in issues that have arisen and will continue to arise when genetics, reproductive technology and parenting practices coincide.

**A J Newson**

### **Living and Working with the New Medical Technologies: Intersections of Inquiry**

Edited by M Lock, A Young, A Cambrioso. Cambridge University Press, 2000, £15.95/US\$24.95, £42.50/US\$59.95, pp 295. ISBN 0521652103

This collection of essays is the outcome of a conference addressing the problems arising from the conjunction of medicine and the humanities with the ever more pressing concerns of bioethics. Since this is a fairly recent development the introduction summarises the argument about what constitutes science and whether it is culturally located. Throughout this well-produced book there is room for discussion and dispute as is inevitable in any interdisciplinary work.

The first part of the book lays the theoretical foundations. Rheinberger discusses the enormous change in the ability to control the biological make up of mankind that molecular medicine and gene therapy offer. This will effectively end the nature/culture juxtaposition. These deliberations are then placed into a philosophical perspective by Rabinow.

Part 2 moves into the real world of laboratories and clinics. Lowy discusses the important role that the concept of controlled randomised clinical trials plays in introducing scientific rigour into medicine (in fact this preceded molecular biology by many years), leading ultimately to the development of centralised, multicentre trials of cancer drugs involving close collaboration between research labs, industry and clinics, this in turn leading to quasi routinisation of dealing with incurable diseases. A comparable case is the search for anti-HIV drugs by desperate patients, which has become an interplay between pharmaceutical firms and governmental agencies dependent on the cooperation of patients willing to take part in the trials. Thus politicisation begins to move the debate out of the purely scientific arena; and AIDS activists have gained a definite, though limited, influence which highlights the social science component of modern medicine. Clinical interviews in relation to pathological investigations show that patients have a part to play in making both clinical and surgical decisions, which in turn are influenced by wider social considerations of cost and efficacy. Throughout it is emphasised that decision making in diagnosis and subsequent treatment depends on various kinds of authority, literature, people's own experience, and a spontaneous sociology or philosophy of the science in question. Young's discussion of post traumatic stress disorders also emphasises fashion in psychological diagnosis and the sociocultural location of interpretation of mental states.

In part 3 Kaufert examines breast and cervical screening as techniques and airs the debate on whether such screening is cost-effective and at what price to individuals at risk from false positives. Looking at Down's

syndrome children, Rapp highlights the disjunction between technological advance in genetics and biotechnology and the human response of families who care for such children. A further chapter deals with “bio-mental” or “biosocial” conditions, notably MCS (multiple chemical sensitivity) and finds that in the light of conflicting interests and under-funded research any explanation of these sociomedical disorders is likely to be temporary and locally determined. The last two essays deal with organ transplantation and unpack the problem of the dichotomy of the “gift of life” that organ donation from brain dead persons presents, versus any sentiments concerned with keeping dying patients intact—a dilemma that is much felt even within the medical profession. Approaches differ between the US and Japan. The ethical dilemma is compatible but at present there are various solutions. Ethics are generally more implicit than overt but it is agreed that they are diffusely socially determined. The final essay, which considers the ethics involved in transplant procuring whether by gift, selling or cadaver donation, finds that regulations aimed at safeguarding certain rights may themselves infringe customary perceptions of what is moral. Some of the problems would benefit from an anthropological approach that takes account of the specificity of small local communities.

There are no final answers in this book, but the at times diverse essays bring together highly topical discussions about the rights and wrongs of a world that is just opening up.

**C R Barber**

## Animals in Research: For and Against

L Grayson. The British Library, 2000, £35, pp 300. ISBN 071230858X

The use of animals for the purpose of scientific research is an emotive subject. The moral arguments often exhibit polarised positions: the scientific demand for absolute freedom of research, and the abolitionist demand for a total ban on all animal experiments. At one extreme are those who argue that research on animals is essential in the battle against disease, and on the other extreme it is argued that the cost in terms of animal suffering is too high and that if experiments were prohibited medical researchers would find some other means of ensuring scientific progress. The rhetoric employed is also suggestive of a polarity: experimenters are accused of cruelty and indifference, whereas campaigners on behalf of animals are accused of irresponsibility and insensitivity towards the wellbeing of humans. Yet to ask which side is right is to betray a misunderstanding of the complex nature of the debate, in which a plethora of interrelated ethical and scientific issues find expression in a wide spectrum of viewpoints.

One of the strengths of *Animals in Research* is that Grayson recognises the complexity of this issue, and in the opening chapter, which surveys the moral and philosophical debate over animal research, there is an appeal for constructive listening. Avoiding either extreme, Grayson opens with a comprehensive survey of the many different standpoints that have found expression in the animal research debate. The second and third chapters focus on public perspectives on animal research and the development of legislation and regulations since the Victorian period. The fourth chapter investigates issues that have drawn

the attention of scientists and animal rights and welfare groups since the 1886 act which dealt with research on animals.

As in most ethical debates neither side offers support for needless suffering, and the way forward lies in the consideration of ways to minimise any necessary suffering both in general and individually. Chapters five and six therefore address the three Rs (replacement, reduction, and refinement) which have emerged as objectives on which otherwise disparate parties can agree. Replacement and reduction seek to minimise the number of animals used in research and refinement is bound up with the minimisation of pain, distress and lasting harm inflicted upon animals. This discussion is the most significant part of the book, as it indicates the possibility of dialogue and consensus among medical scientists, animal welfare campaigners, government bodies, teachers, and regulatory agencies. Grayson recognises that medical scientists are ethical and shows how the research community have demonstrated that scientists are taking legitimate concerns about animal welfare seriously. She refers to the British Association for the Advancement of Science which maintains that continued research involving animals is essential for the conquest of many unsolved medical problems, but recognises that those involved must respect animal life, using animals only when essential, and should adopt alternative methods when available. Grayson also refers to a survey of British doctors in 1993, which indicated 94% agreement that animal research was important to medical advance, while 92% favoured more investment in the development of non-animal alternatives (page 36).

The final two chapters look to the future. Grayson argues that the debate on animal research is likely to intensify, with concern over transgenic animals and the use of animals as organ transplant sources. For those who are interested in the ongoing debate over animal research the final chapter provides comprehensive details of relevant organisations and web sites.

This is an excellent introduction to the animal experiment debate. Each chapter is carefully balanced and is free from the emotive rhetoric which so often clouds the arguments. Moreover, there are summaries, lists of publications, and information about interest groups which are relevant to each standpoint covered in the book. *Animals in Research* is an essential source for teachers and researchers in the veterinary sciences, and it will be of considerable value to the ethicist who is concerned with the broader moral issues related to medical research and human wellbeing.

**D Lamb**

## The Foundations of Christian Bioethics

H Tristram Engelhardt Jr. Swets & Zeitlinger, 2000, 95 DF, US\$39.95, pp 414. ISBN 902651557Xp

In this book, H Tristram Engelhardt Jr outlines his interpretation of Christian bioethics. His branch of Christianity, termed “traditional Christianity”, is described as “the Christianity of the first millennium”. Authority is derived from the church fathers (whose works are continually cited) and from the church community, in accordance with “the Spirit” (this is contrasted with Western Christianity’s use of scriptures and philosophical theology).

In the first half of the book (chapters 1–4) Engelhardt describes the contemporary moral

condition, characterised by moral diversity and fragmentedness. He bemoans the eroding effect of pluralism on moral values and the lack of mechanisms to distinguish between opposing value systems. He terms the present state of affairs as “liberal cosmopolitanism” and argues that the only available moral authority derives from the “principle of permission”—that is, moral authority legitimised by the autonomous choices of those who collaborate; it is procedural rather than objective. In the course of these chapters Engelhardt proceeds comprehensively and persuasively to argue that “liberal cosmopolitanism” is not morally neutral but is a powerful moral framework itself—upholding the values of liberty, equality, autonomy, and toleration—and requiring adherence and belief.

Engelhardt’s thesis is that “liberal cosmopolitan” ethics, and by extension bioethics, is fundamentally flawed, because the search for universality has sacrificed moral authority and hence moral content. On these grounds he dismisses both secular and “post-traditional” Christian ethics and bioethics. “Traditional Christianity”, in contrast to “liberal cosmopolitanism”, embraces authority (mediated through noetic experience, ie experiential knowing of God) and exclusivity (terms such as “fundamentalist” and “cult” he dismisses as political; intended to malign those who are not of the “liberal cosmopolitan” majority). Consequently, “traditional Christianity” is in conflict with “liberal cosmopolitanism” since it endorses patriarchal and sexist views which are offensive to the liberal majority, and as a result traditional Christians find themselves in a hostile environment.

The second half of the book (chapters 5–8) focuses upon the practical implications of adopting this version of bioethics. There are few surprises here, as the practices which are endorsed and forbidden are broadly similar to other conservative Christian traditions. For example, contraception is forbidden, as is abortion and prenatal testing (there is no ensoulment in “traditional Christianity”, therefore, disposal of zygotes and embryos is “murder”, as is abortion in general). In addition, little assisted reproduction is allowed: artificial insemination by husband is permissible if the wish for a child does not interfere with the couples’ spiritual quest and if there is no third-party involvement (sperm must be collected during intercourse or stimulation by the wife and the husband must carry out the insemination procedure). Of particular interest for bioethicists in this section are the differences which Engelhardt highlights between “traditional Christianity” and more familiar Christian approaches. For example, he rejects frequently cited Roman Catholic doctrines, such as the “doctrine of double effect” and arguments which appeal to biological “naturalness”.

This book contains many interesting insights (though perhaps more for theologians and philosophers than for bioethicists), but would be unlikely to satisfy a reader looking for engagement with the practical dilemmas of bioethics. However, since Engelhardt’s intention is to return us to a first millennium Christianity, this is not entirely surprising. His focus on the first millennium leads him to leave out some subsequent advances which have a bearing on his argument; for example, the current philosophical revival of moral realism is not mentioned. This said, the book has much to recommend it, such as an insightful analysis of difficulties which attach to moral pluralism and revealing comments about the philosophies of Hegel, Kant and

Kierkegaard, as well as an introduction to the ethics of Orthodox Christianity. On balance, however, this book will perhaps seem somewhat irrelevant to contemporary bioethicists, although it may prove of more interest to theologians, especially those of the more conservative persuasion, such as the emerging school of radical orthodoxy. Ultimately, the difficulty with Engelhardt's position is communication. His rejection of "liberal cosmopolitanism" leads to an unwillingness to compromise, which makes it difficult for those from the "liberal cosmopolitan" world-view to hear his points; this is somewhat problematic given that his intended audience is the academic community.

**H Widdows**

## NOTICE

### **A Cross-cultural Dialogue on Ethical Challenges in Healthcare**

An international conference on health care ethics, A Cross-cultural Dialogue on Ethical Challenges in Healthcare, is to be held in Abu

Dhabi, the capital of the United Arab Emirates, from 10–13 March 2002. It is being organised by the UAE Ministry of Health. Co-sponsors of the conference include the World Health Organization (WHO), the Islamic Organization for Medical Sciences (IOMS), the International Association of Bioethics (IAB), the Emirates Medical Association (EMA), and the Gulf Center for Excellence in Ethics (GCEE).

As the first such conference in the Arab and Muslim world, it aims to bring together scholars and experts from around the world to address a wide range of ethical and social considerations in the planning and delivery of health care.

The objectives of the conference are to: promote a cross-cultural dialogue towards agreement on universal standards of health care ethics; highlight the Islamic world's contribution to this process; enhance awareness and knowledge of contemporary ethical issues in health care, and to build national and regional capacity to address complex bioethics issues against the backdrop of rapid advancements in the health sciences.

The conference will examine a broad range of contemporary health care ethics topics

including: current controversies in research involving human subjects in developing countries; ethical decisions and considerations in clinical practice; social issues in genomics; strategies for allocating scarce resources; access issues in health systems, and building a bioethics capacity and infrastructure in the UAE, Gulf region, and Arab world.

For copies of the conference programme and registration forms please contact: Dr Basil A Badir, Conference Coordinator, Ministry of Health, PO Box 26094, Abu Dhabi, United Arab Emirates. Telephone: + 971(2) 6330186 and +971(50) 6325110; fax: +971(2) 6321878 and +971(2) 6349225; email: moh\_basilb@hotmail.com and ethics\_conf@moh.gov.ae Website: <http://www.uae.gov.ae/moh/start.htm>

## CORRECTION

In the December 2001 issue of the journal the Book reviews section was incorrectly headed Letters. We wish to apologise to readers for any inconvenience this error caused.