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## Book reviews

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### **Training Manual on Ethical and Human Rights Standards for Health Care Professionals**

John Havard, London, BMJ Publishing Group, 1999, 71 pages, £5.00.

This manual is designed to provide teaching modules on medical ethics for health care professionals in developing countries. The author acknowledges that, although there are common themes, their medical ethical dilemmas are often quite different from those which occur in developed countries and the approach needs to be somewhat less Western in orientation. Emphasis is properly given to topics such as AIDS/HIV and the status of women and children which create special local problems. Although universal principles of medical ethics are affirmed, care is taken to avoid the trap of imposing "our" views and solutions on "their" situations. As a teaching aid the manual is well constructed, starting with the enunciation of general principles, followed by comment and a series of well-conceived clinical examples, each of which embodies several different ethical problems. The manual has a tendency to mix up examples of pure bad medicine—negligence, incompetence, rudeness, lack of compassion—the sort of things that might bring doctors to the attention of the General Medical Council in this country; and examples of clear ethical dilemmas, resolution of which is seldom easy and is not necessarily a function of good or bad practice. I believe a distinction should be drawn between the two. Doctors who practise bad medicine need to be condemned or punished if the offences are serious or repeated, or given a warning or advised to retrain or to work under supervision if they

are not serious or repeated. Doctors who make the "wrong" decision in an ethical dilemma may be acting in perfectly good faith and practising perfectly good medicine. The essence of an ethical dilemma is that there is usually no simple correct solution. If there were, it would cease to be an ethical dilemma and all the medical ethicists and philosophers who have made a career out of the subject could find something else to talk or write about. Each problem has to be analysed individually and the solution directed towards doing the best thing in the interests of the patient or, occasionally, of others, including the community. Perfectly sound and reputable doctors or philosophers may hold opposing and irreconcilable views. In the teaching of medical ethics this point should be emphasised. I failed to find it in the manual, but perhaps Dr Havard intended it to emerge in the case discussions.

At a personal level I was sorry to note the adherence to uncompromisingly orthodox views about some topics. Is it not time for us to reconsider our judgment that payment for participation in medical research is a bad thing? We allow people to work for money in far more hazardous occupations, for example deepsea diving, fishing and underground mining (in South Africa nearly 890 gold miners have been killed in the past two years); why not in far less risky reputable medical research? And is the possibility of carefully controlled trade in organs for transplantation so abhorrent that we cannot even discuss it? In both cases there is a risk of exploitation, but there are ways of minimising this, and there could be clear benefits to seriously impoverished people who have little opportunity to find alternative sources of money. Are we in danger here of doing just what the manual purports to avoid, namely imposing our set of values on others whose circumstances are quite different?

Apart from these admittedly idiosyncratic comments, I think this is an admirable manual. I hope that in the future Dr Havard will produce an expanded version which will include more detailed discussion of the answers to the searching questions he poses at the end of each clinical vignette.

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### **Human Germline Gene Therapy: Scientific, Moral and Political Issues**

David B Resnik, Holly B Steinkraus and Pamela J Langer, Austin, Texas, R G Landes Company, 1999, 189 pages, US\$99.00 (hb).

This book provides a worthwhile and challenging introduction to scientific and moral issues in germline gene therapy. It contains two parts, dealing with scientific and moral issues respectively. In the first, scientific part, a chapter on what the alternatives to germline therapy are is helpful, especially in pointing out that many of the goals one might want to achieve by using germline therapy may be achieved, at a slighter risk, by using non-genetic technologies such as selective embryo implantation and selective abortion. However, the authors argue that germline therapy may be an option in certain cases in which these alternatives are not viable (page 72).

In the second part of the book, moral and political issues in germline therapy are discussed, such as the distinction between therapy and enhancement, potential benefits and harms, rights and responsibilities, justice, our concept of humanness, and public policy issues.

The authors present an argument from parental rights to the effect that parents have a right to use germline therapy (page 117). This right, however, may be restricted in order to prevent harm to others, such as the children who will result from such therapy. The authors conclude that, since germline therapy would not be in the best interest of children (or further generations) at this point in time (due to various technical difficulties and uncertainties), it would be irresponsible to perform it, although this situation may well change in the future (page 119).

Under what circumstances, however, may we say that a child has been harmed by germline therapy? If a particular child will come into existence whether or not germline therapy is performed, then, sometimes, it may be harmed by having (had) the therapy performed (if, for example, the therapy accidentally causes it to develop cancer); it may be worse off than it would be had the therapy not been performed. But typically, the numerically *same* child will not come into existence whether or not the therapy is performed (perhaps, if the therapy is not performed, no child is produced, or perhaps the parents do not opt for IVF, or perhaps, if they do, a different embryo is implanted). In such cases, then, it seems that a child is only harmed by germline therapy if its life is worth not living. And arguably, this will not be the case very often.

However, the authors prevent themselves from claiming that a child who would not have come into existence, had germline therapy not been provided, can be harmed by this therapy, because they take existence and non-existence to be evaluatively incomparable (page 122). So it seems that, according to them germline therapy can only harm a child if it would exist whether or not the therapy were performed, and be worse off if it were performed. But this does not seem to restrict parental rights much.

In an illuminating chapter on justice, the authors argue that germline therapy may affect human equality. We can imagine a society in which the people who are able to pay, provide genetic enhancements for their children, who are then (further) advantaged as compared to children whose parents are not able to pay. Germline therapy may affect the range of opportunities a person has and so may affect (lessen) equality of opportunity. While such consequences could be avoided if genetic enhancements could be effec-

tively forbidden, the authors believe it is both unrealistic and wasteful to forbid enhancements. Instead, they suggest that we should allow genetic enhancements within a genetically “normal” range (page 135). I think that this suggestion has some plausibility, but I should like to make two comments. Firstly, even within the boundaries of what is genetically normal, germline enhancements may promote inequality of opportunity. And secondly, the authors reject a ban on genetic enhancements, in part because they believe it is unrealistic, since governments and private citizens have strong interests in such enhancements. But they provide no reason to believe that a ban on enhancements beyond what is genetically normal would be invulnerable to such pressure.

After the chapter on justice comes a chapter on how germline therapy may affect our humanness. Amongst other things, the authors discuss—and reject—the view that germline therapy may be wrong because it is unnatural. So, while there are some uses of germline therapy that are unacceptable, this is not because they are unnatural, but rather because they harm or demean people.

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## **Behavioral Genetics. The Clash of Culture and Biology**

Edited by Ronald A Carson and Mark A Rothstein, Baltimore and London, The Johns Hopkins University Press, 1999, 206 pages, £33.00.

This book is a collection of essays on recent findings in behavioural genetics and on the appropriate ethical, social and legal reactions to these findings. The authors come from various fields. The collection does not attempt to answer systematically all the questions it raises, but I believe that the book might be of some use in attempting to systematise and analyse the ethical problems in this area.

Behavioural genetics is not in itself a new field of research. We are painfully aware of the claims made for the existence of genetic factors in behaviour throughout the twentieth century. “Eugenics” is today charged with very negative feelings, and there is a risk that any claim by modern scientists about a genetic basis for behaviour,

such as intelligence, will arouse these feelings. This happened when Herrnstein and Murray, in *The Bell Curve* (1994), claimed that there is a racial variation in the genetic component of intellectual capacity and made controversial claims on this basis. This is a fitting illustration of the need to do precisely what the authors are trying to do in the present book, namely “standing back in contemplation” (page x) about the place of behavioural genetics in today’s and tomorrow’s society.

What is new in modern behavioural genetics? First, scientists are able to identify with greater precision, genetic links to alcoholism, criminality, thrill seeking, aggression, sexual orientation, Huntington’s disease, schizophrenia, dyslexia, anxiety and so on. Second, the potential to *identify* the particular genes or gene complexes that lie behind behaviours and diseases looks likely to increase rapidly, thanks in large part to the Human Genome Project. Third, with increasing gene identification will come the increasing possibility of gene therapy.

Many of the questions concerning how to handle this new technique have important ethical dimensions. Here, by means of example, I just want to mention some of the ethical problems that the second point about gene identification raises.

I believe the central question here is what kind of genetic knowledge we want to have. There may be an instrumental value in knowing what will enable us to cure antisocial behaviours and diseases; but what is the value—apart from being a prerequisite for a future cure—of identifying genes that lie behind traits, behaviours and diseases that cannot be changed or cured? According to Allan J Tobin, in this volume, the enthusiasm for seeking this knowledge seems to be higher among people for whom the information is abstract, compared to people for whom it is immediate: “For physicians, genetic tests are like any other diagnostic tool, but for people at risk, they lead literally to life-and-death decisions. In one case, for example, a genetic diagnosis for Huntington disease, delivered over the telephone, was the immediate stimulus for suicide” (page 3).

In some cases there may be a positive value also, for the most immediately affected. David C Rowe and Kristen C Jacobson claim that the findings on schizophrenia have been welcomed as a release for the parents and particularly for the mothers, who

no longer have to blame themselves “for fostering the illness in their children by their supposed emotional coldness and inconsistent discipline” (page 14). But in this regard there is a slight tension in this book between different contributions. For the book ends with Troy Duster’s chapter, which emphasises the danger that genetic test results might lead to the blaming of parents as the genetic source of their child’s disease—children sometimes refer to their genetic disease as something their parents gave them—and I fear that this question of guilt and blame will be even more important in the future, also as far as schizophrenia is concerned. Provided that no cure is found for this disease, may not parents in the future who knew they had the gene for schizophrenia have to explain why they brought children into the world?

These questions and many others could do with a more systematic treatment than is the case here, but once again, that is not the ambition of this particular volume.

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## Ageing, Autonomy and Resources

Edited by A Harry Lesser, Aldershot, Ashgate, 1999, x + 245 pages, £39.45 (hb).

We should be passionate about the elderly. This book contains, albeit with the occasional lull, some passion, adroit philosophical argument and fascinating social and political insights. It originates from a conference in 1992 and, despite talk of Mrs Thatcher, the book has aged well. The first half deals with autonomy in the elderly; whilst the second considers the allocation of scarce resources. The shift from ethics, via clinical practice, to economics and politics is effected with little effort, precisely because of the book’s passion. For it deals with real problems that affect individuals and nations.

I wonder if autonomy was a Thatcherite notion? We loved it in the individualistic 1980s, but its appeal has lessened. It does not solve all our problems and is, perhaps, a hindrance to some elderly people. Dunn links it to being human and to human needs. I am sure autonomy relates to being human, but (as Lamb recognises) so

does dependency. The human need, for love, respect and dignity, is more strongly indicative of our dependency than of our autonomy. The real focus here, I suggest, should be on the person, not on autonomy.

Hostler provides a rigorous analysis of personal development and what it might mean in old age. It is worth noting his important final point, that our models might determine the facts we can see. Models can be limiting, whereas our everyday concepts have more breadth. And Chadwick suggests, surely rightly, that “ageing” is multifaceted. It struck me that we need deeper unpacking of the notions being considered: what can we say about the person, about models, or the everyday use of concepts?

Gavin Fairbairn’s clear use of everyday concepts, however, is counterintuitive, if not perverse. Allowing someone to die, he says *deals* death. Well, they certainly die if we allow them; and death is a consequence of our allowing them. But in what sense do we *deal* them death? They just die. Furthermore, according to Fairbairn, killing might *venerate* life. Sure, it might end suffering, but only by ending life. It perverts language, however, to suggest that aiming to end life somehow respects it. This is to *venerate death* and that will not go down well in the dock.

I was more impressed by the clinical insights of Winner and Herzberg. I take comfort from Winner’s assertion that: “A good clinical service is one that has a small but definite incidence of discharges that go wrong” (page 65). We should be on the side of vulnerable elderly people, even if this involves some risks. Especially if, as Herzberg describes, the alternative is to sit forlornly “staring blankly at a budgerigar or television” (page 73).

Attfield repeats his point, made previously in this journal, that our moral obligations in medical ethics have an international aspect. The point seems cogent, but its punch is softened by inequity at home. Paul Johnson teases out the complications surrounding lack of fairness in the distribution of economic resources. As we await the report by the royal commission on long term care, his discussion of inter-generational transfers is illuminating, if disconcerting. Seemingly, what it is right to do might just have to reflect what is possible. But that conclusion deserves more philosophical scrutiny. As Cribb asserts, moral and political decisions on this macro level are decisions about what kind of society we

want to live in. This will depend upon individual concrete choices. What we should not do, however, is choose “to devalue the latter part of a normal life span” (Leaman, page 186).

Institutions which deal with the elderly should certainly invest in this book. The issues it deals with are crucial: not least of all, the issue of ageism. In his own chapter, Lesser convincingly declares that, in dealing with questions concerning the rationing of treatment, although the effects of ageing might be relevant, chronological age is not. He concludes, passionately and appropriately: “we should be tough-minded and unsentimental, and resist the temptation to do what will almost certainly do no good, simply because we feel we must do something. But we should not pretend that easing or extending a person’s final years, or months, or even days, is ‘doing no good!’” (page 211).

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## Bioethics: A Christian Approach in a Pluralistic Age

Scott B Rae and Paul M Cox, Grand Rapids, Michigan and Cambridge, UK, Eerdmans, 1999, x + 326 pages, \$24.00/£15.99.

In a morally pluralist, or in Alasdair MacIntyre’s terms “morally fragmented”, society it seems almost inevitable that people engaging with issues of bioethics should operate within something like John Rawls’s idea of an “overlapping consensus”—the area in which there is broad agreement between people with different comprehensive worldviews, and in which they are able and willing to operate with the shared criteria of what Rawls calls “public reason”. There are, of course, those who are uneasy about this approach, usually because they see moral fragmentation as being more pervasive and consensus more difficult to achieve, than the Rawlsians believe. From opposite wings Alasdair MacIntyre and Tristram Engelhardt join forces to question the viability of the liberal consensus.

There are, of course, problems with an overlapping consensus. People with religious convictions often feel that the

part of their comprehensive worldview that is outside the “overlap” includes the most constructive and important contributions that their beliefs have to offer. They are convinced they have distinctive insights and truths that should affect practice in positive ways. They want to contribute these to public debate because they consider them valid and true, but they often feel that this is not allowed. Theologians who operate in terms of natural law or believe in a rational common morality, have little difficulty in operating in bioethics along with others; similarly, a number of theologians, mostly Protestants such as Paul Ramsey, James Gustafson and Stanley Hauerwas, have eschewed natural law, but engaged very constructively in debates on bioethics.

Rae and Cox are Bible-based evangelicals who attempt to move directly from the Bible and biblical narratives to bioethical conclusions in ways that are sometimes rather problematic, even to other theologians. It is not easy, for example, to see how poetic biblical statements about God “knowing” people in the womb, or being involved in conception really lead to the conclusion that “the fetus is a per-

son with full attendant rights (page 176). Is it really true that the Bible attributes *personhood* to the unborn from the beginning of pregnancy? As far as I can make out, the Bible does not in fact address this question, or make unambiguous and universal assertions one way or another. It is perhaps good to remember with embarrassment that the Genesis 3 account of the Fall as the origin of the pains of childbirth was sometimes used as a justification for denying pain relief to mothers in labour.

In other places Rae and Cox argue more theologically, and assert that fundamental to a Christian approach are general revelation, common grace, and the dominion mandate at creation. This brings them very close to natural law thinking. And this is indeed where they come out, with sensible procedures for handling bioethical quandaries, and some well-argued positions on euthanasia, physician-assisted suicide and abortion. Sadly, their brief treatment of the appalling injustices of the American health care system does not lead to a sustained biblical or theological critique, or any suggestion that things might be different.

Two concluding comments: First, the authors give little if any indication of how their “distinctive biblical insights” might commend themselves to others in a pluralistic situation. This is a pity, because others, like Bill May or Paul Ramsey, have shown interestingly, for example, how biblical concepts such as covenant may helpfully illumine the doctor-patient relationship. In bioethics today there is a widespread openness to well-argued insights from wherever they may come. We all perhaps still need to learn how best to conduct medical ethical debate in the condition of today’s pluralism, and here Rae and Cox’s careful accounts of views and cases can be valuable. Second, Rae and Cox seem rather reluctant to face head-on the ethical ambiguity sometimes involved in the practice of medicine. In some situations there is no clearly right or good way forward; one has to act without the assurance of the rightness of the action. Perhaps it is precisely at the point of ambiguity that the most important contribution of theology is to be made.

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## Book reviews

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### **Building Bioethics—Conversations with Clouser and Friends on Medical Ethics**

Edited by Loretta M Kopelman, Dordrecht, Kluwer Academic Publishers, 1999, 250 pages, £72.00.

We sometimes forget that medical ethics has a history, and that many of the issues we discuss today have already been discussed many times previously. As the field grows older, and the pioneers retire, we are, however, given some opportunity to recognise that there is in fact such a history, and that we could learn much from paying attention to it. A number of histories of bioethics have been published, and collections centred around the work of major figures are also starting to appear.

The present volume is a collection of papers centred around a critical discussion of the contribution of K Danner Clouser to the development of bioethical theory, and to the teaching of bioethics. The authors include Tom Beauchamp, Dan Callahan, Al Jonsen, H Tristram Engelhardt, Bob Veatch, and other well-known names from the first wave of American bioethics. The contributions, and the responses from Clouser, fall in to two groups. The first group is concerned with Clouser and Gert's famous critique of principlism (a term they initially coined in a 1990 paper). Tom Beauchamp and Bob Veatch argue in separate papers that the critique is misguided, partly because it misinterprets the views of principlists, partly because Clouser's own ethical views seem to be open to exactly the same kind of critical arguments concerning lack of theoretical foundation, lack of problem-solving power, and underdetermination of the ethical framework. Not surprisingly,

Clouser, in a response co-authored with Bernard Gert denies that his framework has the flaws he identifies in the principlist approach, and he further refines the definition and critique of principlism.

The second major group of papers is concerned with the pedagogics of medical ethics. What is the purpose of teaching medical ethics (making medical students good problem-solvers or good people)? What are the core elements of the curriculum? And, what is the best method of teaching? The editor of the book, Loretta Kopelman, has written one of these papers, and she puts her finger on the dilemma of how to define the goal of medical ethics teaching. Can we really say that we only provide students with problem-solving skills within the field of ethics, and that we do not care whether they use these skills for good or bad purposes? Will we not have to admit that we also (at least partly) aim at making some of them better persons?

This book is more successful than most in the genre of *Festschriften*. It contains a fair number of personal anecdotes about K Danner Clouser, but they are never allowed to substitute for a frank and critical assessment of his contributions to medical ethics. The responses from Clouser are also very well written and contain important clarifications of his position. I have therefore no hesitation about recommending the book. It will be especially valuable for three groups of people, those interested in: 1) the history of bioethics; 2) the discussion about the theoretical basis of medical ethics, or 3) the problems inherent in teaching medical ethics.

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### **Ethics Codes in Medicine—Foundations and Achievements of Codifications since 1947**

Edited by Ulrich Tröhler and Stella Reiter-Theil, Aldershot, Ashgate, 1998, 357 pages, £39.95

This book is a collection of essays which originate from two, mainly European, workshops in 1996 on ethics codes before, and especially after, the appearance of the Nuremberg code in 1947. The book has previously been published in German, and a number of contributions have been translated from the original German and French manuscripts.

The majority of the 26 papers cover the development of ethics codes from the Hippocratic oath to the present time, but some papers look at possible codes for new areas such as predictive medicine and resource allocation in health care, and some discuss the more general questions of the importance and transcultural validity of ethics codes. The papers are generally well written and clearly argued. There are no serious translation errors, but there are a number of minor annoying translation problems, as when the names of ancient Greek doctors in a French contribution are not translated but given in their French form (“*Celse*” for “*Celsus*” etc).

Very few of the historical papers contain findings that have not been published previously, but by being collected in one volume they make the history very easily accessible. The most philosophically interesting papers are those that discuss the legitimacy of ethics codes and the transcultural validity of such codes. These



papers raise some fundamental questions about the legitimacy of codes produced by official representatives of (a segment of) the medical profession. Can codes regulating the conduct of one party in an essentially two-sided doctor-patient or researcher-research participant relationship be formulated without taking account of the views of those on both sides of the relationship? And, can codes produced by Western medical associations be transferred to other areas of the world without modification? A very interesting answer to the last question is given in a paper by Robert Baker. He argues that the reason the Nuremberg code has transcultural validity is not primarily that it is based on some set of universal moral norms, but that it is a resolution of a universal set of conflicts. Baker argues that wherever medical research takes place in its modern form there will be conflict between the interests and rights of researchers and research participants, and that these inevitable conflicts can base a claim to transcultural validity. Transferring Western codes is therefore not necessarily a problematic form of cultural imperialism, but a necessary corollary of transferring Western forms of medical research practice.

The book is a valuable and up to date resource for anyone interested in the relationship between ethics codes, legal regulation and medical practice and research. Its usefulness as a reference and teaching tool could, however, have been greatly improved by the provision of an index. Despite the lack of an index, however, it should be an essential part of the library of any institution involved in teaching medical ethics.

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## Individual Liberty and Medical Control

Heta Häyry, Avebury Series in Philosophy, Ashgate, Aldershot, 1998, vi+102 pages, £29.95.

This is a short but very interesting book, which repays study. It is essentially a defence and an application to medical ethics of the *principle of liberty* (page 12), that “the liberty . . . of competent, well-informed, free agents must be . . . maximally protected in matters which concern only or mainly

themselves”. Adoption of this Millian principle, which is argued for in the introduction, along with the adoption of principles of equality (that the needs and interests of all should be taken into account) and of responsibility for the welfare of one’s fellow beings; raises, it may be said, three questions: who is a person (and therefore to be taken into account); when is a person sufficiently competent, and when do people have to sacrifice some liberty to help or protect the welfare of others? Chapter 1 tackles the first of these questions, following the defence of the principle of liberty in the introduction; chapters two to four deal with issues raised by the second question—whether voluntary euthanasia should always be opposed on paternalistic grounds, whether a general programme of coercion in patients’ own interests can be defended, and what form of health education is ethically justifiable; and chapters five to seven deal with issues involving the line between individual liberty and social welfare—preventive medicine, treatment of AIDS, and decision making on health issues.

The weakest chapter is the first, which adopts the view of Harris, Singer and others that self consciousness defines personhood, so that to kill a non-self conscious being—for example, a fetus, or a person in a permanent vegetative state—is to do no wrong *to that being*. The problem is that no argument is given: there is only abuse of the alternative position—to suggest, on page 20, that those who take the potential personhood of the fetus seriously think that there is somehow an adult “in” the fetus, is ridiculous—and the pointing out of its dangers, such as making it impossible to justify abortion even to save life. But Häyry’s view has the danger of giving us no reason for not killing neonates whose parents reject them: the issue cannot be settled in this way.

The defence of “Mill’s principle” is better, but still insufficiently argued, though space may have made this inevitable. Many good arguments are given, but full justice is not done to the opposing view, which is not simply “moralist”, but based on the ideas that: (a) “Millians” are working with too limited a notion of harm; (b) one cannot harm oneself without also harming others, and (c) even competent adults are not always the best judges of what will harm them. A defence of libertarianism must deal with these more subtle objections, and not only the cruder ones. Even these

are sometimes caricatured: are we really supposed to believe that “many influential religions and conservative groups” have the “ultimate aim” of criminalising premarital sex (page 85)?!

But the best of the book is in chapters two to seven. Chapter two does an excellent job of refuting the paternalist arguments against allowing voluntary euthanasia (this does not settle the issue, though, because there are various other arguments). Chapter three successfully refutes the arguments for medical paternalism as a general social policy: particularly impressive is the identification of emotional blackmail and dishonesty as being as coercive as legal or physical control. Chapter four is, regrettably, more sketchy, but makes a start in identifying the principles of a form of health education that incorporates respect for liberty and autonomy.

Chapters five to seven, on issues to do with both individual liberty and social welfare, involve surveying the issues rather than pursuit of a sustained argument, even though many arguments are discussed. Chapter five demonstrates very well the number and complexity of issues raised by preventive measures. Chapter six sets out very clearly issues involved in meeting the needs both of those infected with AIDS and those who wish not to be infected. Chapter seven, in contrast, is an argument for liberal utilitarianism in medical decision making, as a framework that can combine meeting individual needs and the needs of society in a way that is impossible if a libertarian, socialist or communitarian framework is adopted. Once again the argument is skilful but too short, and fails to deal with opposing views in their most convincing form.

Hence, the demerits of this book are that it ties liberalism too closely to a dubious theory of what a person is, and it is too short, so that neither the defence of the liberal principle nor its application is fully developed. The merit is that within these limits it makes a good argument for the principle of liberty and some real progress in showing how it should be applied in specific areas. In short, this is a valuable contribution to medical ethics which one may hope the author will develop further in future publications.

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## **Practical Decision Making in Health Care Ethics: Cases and Concepts**

Raymond J Devettere, Washington DC, Georgetown University Press, 2000, 639 pages, £25.25, \$35.

My colleagues and I in Birmingham are always on the lookout for an undergraduate textbook for our medical students, which was why I agreed to review this book. By and large it is pitched at an undergraduate audience and covers many of the areas that one might expect to find in a UK undergraduate medical course (consent, making decisions for the incompetent, end-of-life issues, beginning-of-life issues, research, transplantation and medical genetics). It also has a chapter on managed care, which is less relevant to a UK audience but is interesting none the less. (The case study for the chapter on James Adams who, it is alleged, lost both his hands and feet as a result of delays caused by managed care, is a harrowing but salutary reminder of the weaknesses of telephone health care consultations and the dangers of trying to cut costs using protocols in emergency situations). Other issues (for instance, HIV and mental health) make an appearance within chapters. There are many interesting cases and the commentary on these is generally useful and structured in a way that would facilitate teaching and—perhaps more importantly these days—independent learning. For instance, in his case analysis Devettere has the subheading “situational awareness” where he lists the facts and ethical aspects of each case. This is a fine example to students of how to organise their thoughts around ethics issues and how to pick out the important points of the cases.

There is perhaps more in the way of moral theory than we could expect (at Birmingham at any rate) undergraduate medical students to engage with—but this is perhaps a problem with our medical students rather than the book! The overview of ethics is thorough without being overly detailed. In Chapter three, for instance, Devettere includes a long section called “distinctions which can mislead” and whilst I did not agree with the way some of the distinctions were drawn—for instance the difference between the reasonable and the unreasonable really based on whether the action is ethical or not?—

the idea was a good one and overall I thought it was a useful exercise. Devettere claims to “approach health care ethics from the perspective of an ethics of the good rather than an ethics of obligation . . . more specifically . . . Aristotle’s ethics of the good” (page 21). This is more obvious when he discusses theory and I found myself disappointed not to find virtue-theory-in-action more evident in the case discussions. If this had been achieved it would certainly have made the book more distinctive. This said, the text is a welcome contrast to principlism.

The main disadvantage of this book as a textbook for UK undergraduates is that all the legal references are based on US legislation and cases. Of course, this does not mean that the references are not useful or interesting: the ethical discussion generated is applicable and it is proper that students should have an awareness of the differences in approach in different legislatures. Nevertheless, this is a significant disadvantage. Students are unlikely to buy more than one medical ethics text and I fear, therefore, that this book is unlikely to be adopted as a set text outside the USA. It is, however, worth buying for a library and certainly worth a look for teachers of medical ethics—and I do mean medical ethics, despite its title. For my colleagues and I back in Birmingham it looks like another summer revising our own course materials.

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## **Male and Female Circumcision: Medical, Legal and Ethical Considerations in Pediatric Practice**

Edited by George C Denniston, Frederick Mansfield Hodges and Marilyn Fayre Milos, New York, Kluwer Academic/Plenum Publishers, 1999, 547 pages, US\$155.00.

The book is an exploration of the medical, legal, moral and cultural aspects of the practice of circumcision. The title suggests that the book will cover both topics, male and female circumcision. This, however, is misleading. The main focus of this collection is on male circumcision. This is

problematic because the fact that female circumcision is left with much less attention means the reader may get the false impression that the practice of female genital mutilation (FGM) is not very widely spread or has less serious consequences than male circumcision. In reality, however, FGM is still extensively practised in different parts of the world and due to its radical nature its physical, mental and social effects are usually even more devastating than those of male circumcision. This important fact is undermined in the very first chapter of the book, in which the trauma of male circumcision is emphasised by the claim that the differences between male and female circumcision are mainly man-made rationalisations of the issue rather than based on the persistent structural gender inequality.

The study starts with the historical origins of the tradition of circumcision, showing how the justification for the practice has varied from religious and cultural demands to a number of medical explanations. The first article by Nahid Touba brings out the social connections of diseases by focusing on the role that the practice of circumcision has had in medical history. Removal of the male foreskin has been believed to cure insanity, masturbation, epilepsy, cancer of the penis and even cancer of the cervix of the future wives of the circumcised boys as well as sexually transmitted diseases and particularly phimosis (either as a disease or as a cause of other diseases such as cancer). Even presently the relation between circumcision and HIV/AIDS is still extensively studied and debated. This shows that while opinions on the diseases that circumcision is to be used to prevent or to cure has changed throughout the times, circumcision as such has persistently maintained its place as a medical practice.

While the book gives lots of attention to the traditional religious and cultural justifications of circumcision, it also attempts to explain why the practice has persisted this long in modern societies such as America. Articles by Van Hower and Paul M Fleiss, for instance, note that justifications for the routine operation of circumcision in North America are usually based on alleged medical conditions. Thus, the practice has gained stronger rational justification than is generally given to the religious or traditional demands of many other cultures. The same was earlier true in the case of female circumcision in which a form of clitoridectomy was used both

in Europe and in America either for hygienic reasons or as a medical cure for masturbation and for mental disorders such as hysteria. Since both male and female circumcision were practised by qualified doctors for allegedly legitimate medical indications in the Western countries, they were not considered to be the same brutal and intervening mutilations of the human body as they were seen to be elsewhere in more primitive societies. This shows that the medicalised nature of Western culture itself can give legitimisation to even violent and unnecessary physical interventions of the human body in the name of science, progress, normality and health.

In this context particularly worthy of note is the comparison between the United States and Europe in the case of male circumcision. The study shows how in the United States, due to the widespread diffusion of the "scientific myth", the medical data with counter-results was deliberately ignored or misinterpreted. For instance, the latest reports from European medical research on the issue were neglected in order to maintain the practice even when it was already rapidly disappearing in Europe. An additional explanation for the maintenance of the practice in modern, market-oriented American society is found in the commercial exploitation of children through circumcision. Physicians, in cooperation with transnational biotechnology corporations, look for the sales of marketable products made from harvested human foreskins, that can be used in the pharmaceutical industry.

In this book the legal and ethical aspects of the practice of circumcision as well as its physical, mental and social consequences are, for the most part, discussed from medical and empirical points of view rather than set within a wider framework of philosophical ethics. Nevertheless, the book takes a clear ethical stand against the practice and the articles show plausibly how little factual basis the religious and cultural justifications of the practice have, even in cases based on medical rationalisation. All in all, the book is useful not only for medical professionals but also for philosophers and ethicists.

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## Introduction to Medical Law

Peter Marquand, Oxford, Butterworth Heinemann, 2000, 125 pages, £15.99 (pb).

Peter Marquand is a medically qualified solicitor who understands the informational needs of medical professionals. Thus, it is not surprising that the topics covered in this book are those most likely to be of practical use and concern to medical and ancillary professions. This publication is clearly a guide, and not an exhaustive text, on current legislation and case law relating to medicine. As a guide, it admirably achieves its objective of providing an overview of contemporary issues of relevance in the medical field.

Marquand's research summarises the fundamental principles of, and legal responses to, the standard topics covered in medical law texts such as clinical negligence, consent, capacity, withholding or discontinuing treatment, confidentiality and abortion. Additional subjects not ordinarily covered in such texts include: the coroner's inquest, drugs and prescribing and postmortem examinations. The preventive potential of this book and its practical value, are evident in the chapters which address risk management, defending a negligence claim, and expert testimony in civil cases.

Marquand has successfully achieved a goal which may appear deceptively simple, but is in fact formidable, and will be widely appreciated. Educators who have developed training for non-lawyers will understand the difficulty in disseminating current, succinct, and relevant legal information in an accessible format. Accordingly, this book is essential reading for the undergraduate and the continuing professional education of doctors, nurses, psychologists, health care workers, and allied professionals. Also, it will be of particular value to those professional bodies which are developing their own professional guidelines, often in the absence of legal training. It lacks, however, sufficient detail to be a definitive manual for medical professionals, as is acknowledged in the foreword, which warns that the guide is not a substitute for legal advice.

One concern, which may be addressed by that warning, is that the book does not consistently address some procedures which are frequently undertaken and which warrant more

detailed discussion and citation than that provided. For example, abortion is discussed in four pages and supported with seven references, despite the substantial research and discussion which abortion has generated in this jurisdiction and elsewhere by ethicists, lawyers, doctors, feminists and those of other professions. More extensive citation to related research and additional academic texts which comprehensively discuss the subject matter of the briefer chapters would extend the relevance of this publication to, for example, postgraduate students.

However, this guide should be praised for what it is. It explores the parameters of medical law with the appropriate amount of detail for those who seek a broad understanding of the legal principles which govern the interface between the legal and medical systems. The book does not aim to generate provocative critical legal debate nor does it explicitly include an ethical component. Rather, it provides a firm grounding in how the law has been constructed, and how it responds to issues of fundamental ethical significance such as discontinuing treatment and treating the person who lacks capacity. Thus, it provides a solid framework for understanding the state of medical law in England and Wales in 2000, thereby contributing to the accuracy of those debates. What Marquand promised, Marquand delivered in a concise, entirely comprehensible, and affordable volume.

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## Biomedical Ethics Reviews, Is There a Duty to Die?

Edited by James M Humber and Robert F Almeder, Totawa, New Jersey, Humana Press, 2000, 221 pages, US\$49.50.

At the heart of this book is the idea that we would all be better off were we able to recognise the harder, slower, more expensive and more unjust dying which the continued development of modern medicine offers. The proposal is perhaps not so much a duty to die as a duty to refrain from unfair or excessive use of health care resources and to



refrain from imposing excessive burdens at the end of one's life on family or friends. On the global scale, Battin invites us to consider a huge international deal to be struck between the wealthy First World and the developing Third World. Backed by figures on life expectancy in different countries and by some financial information, Battin is persuasive in identifying the wrong of excessive, expensive life-prolonging health care in a world where basics such as clean water, inexpensive vaccines, and ordinary family planning and reproductive health care are unavailable to so many. In short, "we ought to die sooner so they could live longer". But this is only a part of the deal. The two other necessary elements are a) mechanisms to convey the savings from a person's earlier death in the First World to fund health care and related measures that would increase life expectancies in the Second and Third Worlds and b) the identification of the health-related obligations of people in the Third World to those in the First. We insist, for instance, that the rain forest ought not to be cut down, that the sea and the air should not be polluted in the way that happened in the developed world's early industrial development and that nuclear weapons should not proliferate. Although it is acknowledged that this line of argument depends on the future existence of effective international redistributive structures, our attention is drawn to this as a lack of vision, a lack of political will rather than a flawed argument. As Battin hoped, the deal outlined did strike this reviewer as more of a real challenge to our moral selves than a silly thought experiment.

Of the subsequent eleven chapters, each written by a different author, six are sympathetic to the claim that there is a duty to die. At the national level it is suggested that public policy could achieve significant redistribution of resources and at the family level, emotional as well as financial burdens might be reduced.

At least three contributors cast doubt on the existence of a duty to die and one (Tong) argues that it is not even safe to posit such a duty, given societal inequalities which might make any imposition of such a duty unfair. Having been taken on an interesting and for the most part well-written tour of this question, in the last two chapters a somewhat diluted and perhaps more plausible conclusion is offered; that although we may not have a duty to die, sometimes we do not

have the right to something which is necessary to sustain our lives. Spelcey suggests a duty more akin to a debt of gratitude, which might be owed, but which it would be improper to demand. This book, the seventeenth annual volume of "Biomedical Ethics Reviews", achieves its aim of discussing in an accessible, enjoyable and informative way a question of importance to most of us.

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## Recovering the Nation's Body

Linda F Hogle, New Brunswick,  
Rutgers University Press, 1999, 241  
pages, US\$22.00 (pb).

Drawing upon the disciplines of bioethics, anthropology and politics, Linda F Hogle examines the use of human body parts for transplantation and research in modern Germany. She focuses on German attitudes to organ transplantation and the fears expressed by doctors and the public regarding utilitarian justification of the use of body parts taken from the vulnerable to benefit others.

In modern Germany, argues Hogle, organ transplantation and practices relating to the use of human body parts have developed under the shadow of the history of medicine during National Socialism. This can be seen in the recent controversy over brain death, where the spectre of "lives not worth living" has been invoked in the context of decisions to declare death and authorise removal of body parts. Ethical tensions were also revealed following the unification of East and West Germany: the former Eastern state regarded human bodies as state property and the Western state endorsed the opportunities for profit-based medicine.

In the first part of the book Hogle discusses various cultural meanings of "the body" in German history, including an account of how the body has been handled at death, various uses of the body, (where she points out that the use of bodies and their parts for healing is not a new phenomenon), German funeral customs, and the unique history of the body under National Socialism. This is followed by a discussion of legal notions of bodily integrity and new ways of regarding the relationships between

the body, technology, and the state. All of this provides a backdrop to an examination of the link between the social and political aspects of organ transplantation and its scientific and technical aspects, which is covered in part two.

The second part provides an in-depth study of procedures for the management of donors and distribution of cadaveric organs throughout Europe, drawing attention to the way regional political differences within Germany affect the procurement of organs and the medical profession's response to the public debate on transplantation. In this context Hogle recounts how the media in Germany provided sensational coverage of medical scandals during the past decade. First, was the Erlangen experiment in 1992, involving the post-mortem ventilation of a woman in order to preserve the life of her fetus. The fetus aborted after six weeks, but during this time confusion reigned over the meaning and diagnosis of brain death, and the incident evoked memories of Nazi medical experiments. The second scandal followed media revelations in 1994 concerning the routine selling of tissues from cadavers in hospitals, which intensified public distrust of doctors and a general feeling of powerlessness in the face of big industry, the state and the medical profession. Under headlines such as "Plundering the dead", the media published photographs of piles of bones, artificial hip joints and large containers of human brains, resembling the piles of human hair, bones, etc, displayed when the concentration camps were liberated. The third scandal recounted by Hogle involved revelations about the use of human cadavers as crash test dummies, which was sensationally reported in 1998. Each scandal emerged with a barrage of media coverage. According to Hogle, reaction to these stories was informed and influenced by the history and memory of National Socialism and it is partly this history and memory that has been responsible for the decrease in organ donation, in Germany, by relatives throughout the 1990s, which contrasts with other European countries and the US. Throughout her extensive surveys and interviews with German medical personnel, Hogle notes, however, that the essential characteristic of German organ procurement practices is the "need to preserve an image of not violating the dead" (page 196).

This is an extremely well researched book and is one of the first serious

attempts to understand the complex variations in ethical attitudes to the dying and the newly dead in contemporary Europe.

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## The Patient Self-Determination Act: Meeting the Challenges in Patient Care

Lawrence P Ulrich, Washington, Georgetown University Press, 1999, 351 pages, £46.75.

This is an extremely readable and interesting contribution. The author takes the reader through the Patient Self-Determination Act in some depth, but doesn't make any attempt to look at its provisions in real detail. This cannot be taken as an omission, as the purpose of the book is to explore the principles underpinning the legislation and to explore its ethical content.

In that respect, this is a very interesting exercise. On one view, the Patient Self-Determination Act did very little to change the current law in the United States. The legislation is designed primarily to ensure that on entrance to any federally funded facility, patients are made aware of the facility's policy on advance directives and withholding and withdrawing treatment. Thus, the legislation does not directly tackle whether these policies are appropriate, but rather it makes a contribution to the information which all patients will have when they make a decision about which facility to enter, and also it may encourage them to take account of these policies in their participation in their own health care. Ulrich reads the legislation as making a significant contribution to the rights of patients to self determination, as well as making the informed consent process more meaningful. To an extent his views on this could be taken as aspirational rather than necessarily real. None the less, the way he reveals the capacity of the legislation to achieve these goals makes for a very interesting analysis of the ethical, social and legal background to the legislation.

In leading us to the conclusion that one ancillary, but in his view, beneficial, outcome of the legislation might be a move towards the assessment of

what is a "reasonable patient", Ulrich—in a very readable manner—explores fundamental principles of medical ethics and explains the extent to which these are met by the terms of the act. This is a very readable book, although it's tempting to suggest that it may be a little overenthusiastic in terms of what this legislation can achieve. None the less, if read by health care providers it should point them towards the rationale for the legislation and remind them of its potential importance.

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## Palliative Care Ethics: a Companion for all Specialties (2nd ed)

Fiona Randall and R S Downie, Oxford, Oxford University Press, 1999, 305 pages, £21.95 (pb).

The main purpose of a book review is to convey to the reader the essence of the book's content, thereby facilitating an assessment of its relevance for specific interests. Book titles alone are usually inadequate and/or misleading and sub-titles are used to be more informative. In this case, the subtitle, *A companion for all specialties*, is not only relevant but incredibly important. Without it, the book might easily be ignored by those who neither work nor have a special interest in palliative care, and more particularly in the care of dying patients. The target readership for this book is very much wider than that. The authors, one a consultant in palliative medicine and the other a professor of moral philosophy, have produced a profound treatise on many aspects of health care by raising ethical issues which permeate all specialties.

In their preface, they present a rough outline of their book, which is divided roughly into three parts. Chapters 1-5 are the more general and express a basic philosophy of palliative care. Chapters 6-12 deal with a range of clinical topics and chapters 13 and 14 raise wider and more challenging philosophical issues. This is not so much a textbook on ethics as a springboard for discussions, seminars and other small group activities which aim to stimulate thinking. Mixed groups, representing various specialties, including lay carers, would benefit enormously from using

this resource. As the authors themselves say, it is often the collaborative dimension, the need for teamwork, which poses the most interesting and important ethical challenges.

This is the second edition of the book, just three years after the first and it has already had two reprints. This edition is the result of feedback from readers and the responsiveness of the authors to changes in the delivery of health care and in consumer expectations, most of which seem to have some ethical implications.

Three significant changes have been made. In the first place, the subtitle has been amended from *A good companion to A companion for all specialties*, which is more descriptive of the book's potential. Secondly, three new chapters have been added. They are: *The relative-professional relationship*, chapter 3; *Reply to critics*, chapter 13, which discusses emotional care and patient autonomy and touches on euthanasia, and *Quality and value of life*, chapter 14. The third change in this new edition is the introduction at the start of each of its 14 chapters of a brief literary quotation, which focuses one's mind on the underlying philosophical issue.

The successful partnership of a clinician and philosopher in writing this book demonstrates the benefits of such collaboration and the bringing together of different modes of thought. The same benefits also find expression in the many examples from the real world of caring which illumine the pages of the text.

In his foreword, Dr Derek Doyle expresses his satisfaction, which I share, that the authors focus on daily ethical issues and problems, such as information giving and confidentiality etc and not on the dramatic ones. Their work is truly reality-oriented and shows due regard to the ever pressing problem of limited resources.

This book represents a superb addition to the literature on health care ethics. It demonstrates the need for experience, wisdom, common sense, sensitivity and professional integrity, all of which are ingredients of a high quality service, though rarely amenable to quantitative measures.

The authors deserve our gratitude and serious attention. I have no hesitation in recommending their book to every person who has the responsibility and privilege of giving any form of health care to another.

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## HIV and AIDS—Testing, Screening, and Confidentiality

Edited by Rebecca Bennett and Charles A Erin, Oxford, Oxford University Press, 1999, 285 pages, £35.00.

If I have any objection to this book, it is to the title, in that it might narrow the audience that would benefit from it. Although the title is formally quite accurate in describing the contents, it underplays the relevance of the arguments set out herein to a very broad range of clinical arenas, for which HIV/AIDS can be a notable example. This fascinating series of essays covering the topics in the subtitle and much more, shows how valuable AIDS has been as a worked example of a series of interdigitating core issues in medical ethics, as it has been in so many areas of clinical medicine, public health and public policy. Although the authors and editors underplay this wider relevance, I found myself, despite my own substantial involvement in HIV and AIDS over the past twenty years, constantly wanting to cross-refer to other clinical areas. Perhaps readers of this review, who are minded to read, or even to reread, this book might take such a perspective.

The editors have managed, by their choice of authors, to organise a very broad range of perspectives. While the styles, compass and approach taken by the authors are quite variable, this is generally a benefit and not a problem, as it enables the reader to appreciate the diversity of views that can legitimately be taken on the same mountain. The format is not an artificially polarised debate (though there are plenty of polar views and opposing perspectives to be found), but rather a series of thoroughly reasoned perspectives, usually set out according to a clearly defined system of reasoning. The introductory chapter by the editors is a valuable guide to the issue itself and to the chapters and their perspectives (and is worth rereading at the end).

I must applaud the authors and editors for a truly informative exploration of some very big issues in medical ethics. The breadth of the coverage is substantial, encompassing ethical and legal

dimensions, and considers some central themes in health care ethics: Is the individual or society responsible for their health? Can health care workers be advocates for third party interests, as well as caring for their patients? There is a thoughtful essay on compensation and consent in relation to transfusion-associated infection, and another on whether a fiduciary relationship can be both an ethical approach and a legal concept. These chapters provide a conceptual underpinning to the more formal exploration of the very thorough coverage of testing, screening and confidentiality—in clinical and public contexts, as well as in research settings. There is a very nicely argued chapter near the end on the categories of people who might want to know the status of a person with HIV, and whether they should. It is, however, rather invidious to select out individual articles when so many are excellent. Similarly, picking out specific aspects of the debate could distort the impression of the impact of the whole, which I found to be deep as well as broad (hence I took an unconscionable time reading it for this review!)

Of course there is plenty with which one could take issue and I could not agree with all the views set out, despite their persuasive style and scholarly tone, but that is the essence of a book of this sort. A few chapters seemed slightly remote from clinical reality, but that distance was mostly used to good effect. One chapter (purportedly giving “an American perspective”) seemed inclined to rewrite the brief history of AIDS from a rather distorted personal and distant view; this was really the only weak chapter in the book. I don’t think most of my American colleagues would recognise this as a fair national perspective. I found it polemical and a barely recognisable account of what actually went on; it might better have been subtitled “the personal perspective of an American lawyer”.

I heartily recommend this outstanding volume to anyone interested in medical ethics, whether or not their primary interest is concerned with HIV/AIDS. It explores the rich perspectives that this terrible pandemic has given us on contemporary medical ethics.

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## Bioethics is Love of Life: an Alternative Textbook

Darryl R J Macer, Christchurch, New Zealand, Eubios Ethics Institute, 1998, 158 pages, £12 (pb).

Love of life is the theme running through the eight chapters of this book, which cover theories of bioethics, the language of love, self love (embracing autonomy, selfishness, and altruism), love of freedom, loving relationships, animal ethics, and environmental ethics. Love of life, says Macer, is the “simplest and most all encompassing definition of bioethics, and it is universal among all peoples of the world” (page 1). This vision of love as a basis for a universal bioethics is part of a more ambitious project intended to inspire the creation of a global community wherein all individuals overcome diversity and work towards a perfect whole. To this end the author attempts to cover a vast range of religious beliefs and cultural traditions.

The opening discussion will be familiar to Western bioethicists, as it covers deontological and teleological theories, ranging across a broad spectrum of recent bioethical writing. The author concludes that the “inner motivation and strength of ethical behaviour comes from love” (page 27). The main objection to an ethical system based on love, claims Macer, is found in the tradition embracing Plato and Kant, who saw emotions and feelings as a distraction. Despite a wealth of literature relating to love, and the fundamental role it plays in the public’s conception of ethics, Macer complains that it has been largely ignored in recent bioethics. This is due to academic snobbery, claims Macer, which is bound up with a desire amongst bioethicists to have a monopoly on prescriptive ethics!

There is an interesting chapter on the boundaries of love towards animals, where “love” signifies an ethical commitment. But on the question whether causing harm or suffering to other animals is bad, Macer appears to follow the route taken by several Western bioethicists who attempt to weigh evidence in support or against claims that fetuses are persons. By analogy, if evidence is produced that some animals have “person traits” or “signs of love” then harming them is wrong.

This position has been dubbed “personism”: it is frequently employed to mark the boundaries of moral obligation to fetuses, animals and patients with severe neurological disorders. Personism, it might be argued, is as arbitrary as speciesism and many other “isms” where a particular group is said to be entitled to preferential treatment.

Macer is to be commended for a rather ambitious attempt to bring together a wide range of religious beliefs and diverse ethical traditions, but the overall impression is that the book attempts to cover too much ground.

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## Medical Ethics and the Future of Health Care

Edited by Kenneth Kearon and Fergus O’Ferrall, Dublin, Ireland, Columba Press, 2000, 168 pages, £7.99.

Public lecture series do not always, unfortunately, result in a published volume of interdisciplinary, informed and well argued papers. *Medical Ethics and the Future of Health Care* has succeeded, however, in doing just this. A public lecture series was organised by the Adelaide Hospital Society, Dublin, Ireland in 1999 to facilitate better public understanding of complex issues in health care confronting citizens and carers. The book assumes correctly that the Republic of Ireland is now indisputably a pluralist society, discomfiting to some readers who might look to the book for absolute answers and certainties. They would be disappointed because the essays show rather that it will be public debate and reasoned, imaginative approaches to decision making in health care that will replace the comforts of traditional certainties.

Coming from the internationally recognised philosopher of principlism, James Childress, the nurse ethicist, Verena Tschudin and representatives from obstetrics and gynaecology, midwifery, legal medicine, psychiatry and psychology the essays are accessible and informative without oversimplifying complex ethical issues. Childress’s essay, Bioethics on the brink of a new millennium, calls for the inclusion of imagination in the

process of deliberation if we are going to achieve the discernment needed for balancing claims of individuals and claims of communities. And such balancing of individuals, professional institutions and communities is also an important component of the theses offered by the other authors. Tschudin encapsulates the wisdom of nursing philosophy in her essay, Ethics and holistic care, which maps out the conceptual connections between development of skills for self awareness, listening and ethics. These links are often ignored in bioethics writing and yet contributions from nursing philosophy allow the necessary expansion of a humane and person-centred framework for health care ethics.

Four of the essays by Denis Cusack, (medical law) Marcus Webb (psychiatry), Patrick Hanafin (law) and Sheila Greene (psychology) home in on the question of patient autonomy and institutional policies and legislation arising in questions about involuntary treatment in psychiatric institutions, the right to die, abortion legislation, genetics and implied transformations in our understanding of “persons”. These four essays are particularly comprehensive and provocative in calling for responsible and sustained public debate as a medium for educating a wider public about the exercise of deliberative democracy in application to health care policy formation.

Cusack’s essay, Autonomy and consent, recognises the value of autonomy while remaining sceptical of the desirability of full implementation in advance directives, or patient rights to information regardless of a doctor’s wish to invoke “therapeutic privilege”. Cusack wants to believe that the health care provider has a right to be “trusted” and that he or she should enjoy the privilege of self regulation. One response to Cusack is to argue that there is no natural right to be trusted and, as with leadership, trust must always be earned.

Hanafin’s essay, Legislating the right to die, is outstanding in its comprehensive perspective on the right to die and the impact of what seems an abstract right on institutional and cultural ideologies which are deeply embedded in Irish state policies, the Irish constitution and ecclesiastical traditions. The superb accuracy of Hanafin’s analysis makes clear that ethics cannot be relevant if it remains aloof from cultural, social and identity contexts. In the final essay of the book the reader is reminded of C P Snow’s *Two Cultures* and his injunction that we

cannot afford a communication divide. Greene argues here that we can’t leave science to the scientists but have to engage in active debate about the values that will guide our choices in the fast developing and promising area of human genetics. While not dodging a caution about a possible “slippery slope” in expanding reproductive technologies, Greene reiterates the bases for genuine citizen autonomy in the area of reproductive options: awareness and informed debate. It is refreshing to read in Greene’s analysis that the problems are not in human cloning as such but in how we in society will perceive and value “clones” who might result from this reproductive process which is likely to be much closer to realisation than Greene predicts.

This is a readable and provocative book of essays which might not challenge professional bioethicists but would be an exemplary text for any study group, lay reader or adult education centre motivated to develop the level of public debate so strongly called for in this fine book.

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## Genetic Information: Acquisition, Access, and Control

Edited by Alison K Thompson and Ruth F Chadwick, New York, Kluwer Academic/Plenum Publishers, 1999, 348 pages, \$115 (hc).

News that the first draft of a map of the human genome had been completed was received with great excitement but fears persist about how this knowledge will be used. Such concerns were the basis for an international conference held in Preston, England in December 1997. The issues addressed were non-existent when many of those attending the conference were born, but they are among the most pressing ethical problems we face today. They are philosophically challenging, and the way we deal with them will have far reaching consequences for both individuals and society. The proceedings of the conference are now available in this book.

Thirty authors, almost exclusively from Western Europe and North



America, have written about the important issues of eugenics, insurance, the effects of market forces and the question of patents, public awareness of genetics and a variety of psychosocial and ethical concerns. Readers with a theoretical bent will find them dealt with more satisfactorily than will those more interested in applied medical ethics. This is the inevitable result of there being no contributors from the coal face such as genetic counselors, medical doctors, actuaries, or "consumers". So while I read with interest, I kept my cardigan on to ward off the chill of the ivory tower.

A fundamental question examined was that of the extent to which genetic information is special compared with other health information. Holm argues (at some points more convincingly than at others) that it is not special since other health information can also be predictive of the future health of a person, of that person's offspring and of his/her other relatives, and that other health information can be as personal and sensitive as genetic information. He goes on to argue that a uniform regulation of all health-related information is better than a specific regulation of genetic information.

The question of what to do about genetic information and health insurance is a crucial one which is dealt with at length. Insurance is essentially a form of betting. Is it "fair" if the insured person knows how the dice are loaded when the insurer does not? Is it "just" to punish someone with higher premiums or no insurance cover because that person has done badly in the genetic lottery? Is it acceptable for insurers to force genetic tests and unwanted knowledge on people? Lemmens argues that to the extent that insurance contracts are commodities, these questions should be subject to

the rules of the market place, but in so far as they have a redistributive role, this should not be the case. He argues that necessities such as health care are not commodities and that public provision is required for health and welfare. Tangwa, the only contributor from Africa, says very succinctly that, "... it does not seem morally right or even ordinarily fair to ... reward or punish people on the basis of involuntary biodata".

This issue of the unfairness of the genetic lottery comes up again and again. Holtug argues that if people are disadvantaged (genetically or otherwise), we should compensate rather than punish them. He points out that this implies more than just health care and also looks at the question of where one draws the line between correction of a problem and enhancement. I wish that more contributors had considered this very delicate and complicated problem. Holtug goes on further to look at the question of responsibility and considers how responsible an individual is for failure in a career if it is due to: (a) lack of talent, (b) lack of effort, or (c) a decision not to pursue that career. He points out that any of these may be due to genetic endowment and/or environmental influences. It could be argued logically that whatever we do is, by definition, what we had to do, and it is puzzling that in our society we hold the individual responsible if the causes are thought to be environmental but not if they are thought to be genetic. Again, I wish more attention had been given to this problem.

As one would expect in a multi-authored book, the style and accessibility vary enormously from one chapter to the next. Some I found extremely interesting while others failed to engage me at all. Overall, the book presents some important questions and explores philosophical ways

of dealing with them. A journey through it leaves the reader better able to dissect the ethical issues in genetics today.

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### Correction

A review of the *Training Manual on Ethical and Human Rights Standards for Health Care Professionals* which appeared in the journal's February 2001 issue mistakenly identified its publisher as the BMJ Publishing Group. The publisher is, in fact, the Commonwealth Medical Association and the manual is available from the Commonwealth Medical Association at BMA House, Tavistock Square, London WC1H 9JP.

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### Books: information and orders

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