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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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