Book reviews

Physician-assisted Suicide: Expanding the Debate

Edited by Margaret P Battin, Rosamund Rhodes and Anita Silvers, New York and London, Routledge, 1998, 463 pages, £45.

This substantial academic volume, which seeks to expand the debate on physician-assisted suicide, is a significant addition to the growing number of edited works on one of the most important issues in contemporary bioethics.

The introduction observes that the essays illuminate the evolving, increasingly "nuanced" American debate in the wake of the landmark Supreme Court decisions upholding laws against physician-assisted suicide. Its twenty-three chapters are divided into five sections: "conceptual issues"; "those at risk"; "the practice of medicine"; "the impact of legislation", and "religious perspectives".

How, then, is the debate said to be evolving? Conceptually, the editors claim, both proponents and opponents now appeal to the same values, such as autonomy, beneficence, and medical integrity. Politically, patients' groups have focused attention on the likely effects of decriminalisation, particularly on "vulnerable" groups such as the disabled and racial minorities. Medically, there is greater recognition of decision making by patients and relatives and of the inadequate provision of palliative care. Religiously, different denominations have extensively examined their respective theological positions. In short, it is claimed that the debate is not only "larger and louder" but also "deeper and more profound".

This well-produced book is certainly a worthwhile contribution to the debate. Margaret Battin is deservedly one of the most well-known writers on

end-of-life issues and she and her fellow editors have produced what is, on the whole, an interesting, readable and topical collection of essays. Whether it succeeds in expanding and deepening the debate is, however, itself a matter for debate.

On the one hand, a number of contributions do help to develop the debate, particularly Patricia King and Leslie Wolf's essay on the perspective of African-Americans, Patricia Mann's on the meaning of death, and the contribution by Margaret Battin herself, which questions the common assumption that physician-assisted suicide should or would be rare.

On the other hand, the book risks giving a misleadingly *narrow* and rather one-sided impression of the debate.

First, although the editors write that they aimed to produce a "fairly evenly balanced" collection, contributors in favour of physician-assisted suicide outnumber those against by around two to one.

Secondly, only two essays oppose physician-assisted suicide in principle, and those for religious reasons. The book's failure to include a single philosophical contribution articulating and defending the traditional principle of the inviolability of human life mars the volume. This failure is all the more unfortunate not only because several essays criticise this principle, and those criticisms therefore are allowed to pass unchallenged, but also because the principle of the inviolability of human life was reaffirmed by the Supreme Court and underpins its reasoning. The volume could easily mislead a reader into believing that the principle no longer plays an important part in the current debate.

Thirdly, moving from principle to practice, another omission is the Dutch experience of euthanasia and physician-assisted suicide, an omission which is all the more puzzling in the light of the significance attached by the Supreme Court to the dangers

of the "slippery slope" and to the relevance of the Dutch experience in this context.

Finally, contributions on the achievements and availability of palliative care, the Oregon law, and on the alleged distinction between physician-assisted suicide and euthanasia, would have been valuable. The book does, however, have useful appendices containing the text of the Supreme Court judgments; the "philosophers' brief" submitted to the court, and the Oregon Death With Dignity Act.

In short, in some significant respects this volume serves to expand the debate. In others, however, it gives a misleadingly narrow impression of it.

JOHN KEOWN,
Faculty of Law, University of Cambridge

Children, Families, and Health Care Decision-making

Lainie Friedman Ross, New York, Oxford University Press, 1998, 197 pages, £30.

Over recent years in the UK there has been increasing emphasis placed on children taking responsibility for what happens to them. This American publication offers a refreshingly different view of parental and family autonomy and advocates a model of constrained parental autonomy. Ross argues that giving children rights equivalent to those of adults is "to deny them the protection they need" and render them "even more vulnerable than they presently are". Her thesis is that whilst children should be included in the decision making process, parents should be responsible for their health care even after the children have achieved some threshold level of competency. However, the autonomy of the parents should not be absolute. Rather it should be constrained by a modified principle of respect for

persons which takes account of the specific limitations of children's competency.

The author herself suspects that she will be criticised for not according enough respect to competent children and that her interpretations may permit of wider parental autonomy than many readers will find acceptable. She addresses each anticipated criticism systematically and argues her case cogently and carefully, presenting argument and counterargument, liberally annotating and referencing her text, and pointing out areas where information is scant or questionable. She recognises that parents' conception of what is best for their family may not be what others would perceive as best and that indeed their beliefs and values may even limit opportunities for children. Nevertheless she believes that their autonomy should be questioned only if their decisions are disrespectful of the child's developing personhood; it is not for the state to define ideal parent-child relationships or goals.

The model of constrained parental autonomy promoted in this scholarly work allows flexibility and breadth of application which, the author contends, makes it practical as a decision making model across a wide range of health care situations. In the second part of the book she tries out the model in various practical contexts: research, organ donation, medical treatment, and adolescent sexual activity. She concludes that it offers a viable alternative to the best interests standard and is particularly useful in situations where interests compete and conflict. Underlying her position is a respect for parents as individuals with their own needs, interests and rights, a fact which she sees as too often ignored. Parental and family autonomy deserve a wider latitude of tolerance than they commonly command.

This slim volume deliberately invites challenge. The author concludes with the hope that the book will promote dialogue on how health care decisions should be made for children even if readers disagree with her "process or substance". Many will indeed disagree with some of her thinking, but she should certainly succeed in stimulating debate.

HAZEL E MCHAFFIE

*Research Fellow, Medical Ethics, University of Edinburgh
Deputy Director of Research, Institute of Medical Ethics*

A Philosophical Disease: Bioethics, Culture and Identity

Carl Elliott, New York and London, Routledge, 1999, 188 pages, £12.99.

Bioethics became established as a distinct discipline in the United States in the 1960s. The paradox is that it arose in part from a general background of criticisms of biomedicine at that time, but has largely followed the traditional pattern of biomedicine in being reductionist and orientated to pragmatic problem-solving. So for some thirty years the theoretical debate within bioethics was mainly about which ethical theory, principle, or combination of principles to subscribe to; whilst in practice many came to see bioethics as a new medical subspecialty, with hospital ethicists as professional experts.

However, this mainstream development of bioethics has not gone unchallenged, and there have always been those advocating other approaches. The Centre for Philosophy and Health Care here in Swansea has been a good example of this, having consistently concerned itself with many of the issues that Elliott raises. These focus on the question of whether any systematic philosophical theorising, or precise arrangement of principles, could ever provide definitive answers to deeply troubling medical dilemmas, because of the inevitability of moral disagreement. Such dissident voices tended to be rather isolated until a decade ago, but since then have increased very significantly in numbers and in a variety of different ways, though united in challenging the earlier orthodoxy.

Elliott does not then provide anything entirely novel, but rather uses several examples to demonstrate how a range of these innovative approaches can provide a different perspective on familiar issues. He has accomplished this by selecting from and expanding on some of his own papers which were published during the 1990s. He has thus converted them into a series of essays which form the central chapters of the book. Narrative ethics and virtue ethics are the most notable approaches he adopts, but he has also added an introduction and conclusion which are explicitly informed by Wittgenstein's later philosophy, with the aim of providing coherence to the book as a whole. What he is attempt-

ing to show is that while at first sight these essays may appear to be somewhat disparate, they actually have a connecting theme. I am not sure though whether Wittgenstein's later work provides an adequate resource for this task, although its general relevance is clear.

To see why this is so it may be helpful to refer to Stephen Toulmin's work, which has been influential in the development of Elliott's thinking. Toulmin has made the bold claim that the philosophy of medicine has a special role to play, not just in medicine but also in philosophy. Now if this is to be fostered successfully I think that a greater range of ideas will be required than can be derived from Wittgenstein's work alone, and this is the programme within which Elliott's ideas would seem to fit most comfortably. However, one significant development in taking this forward is missing in Elliott's book. This concerns the current growth of interest in phenomenology and hermeneutics, particularly in relation to the philosophy of the body, which would seem to herald a fruitful engagement between the Anglo-American and Continental traditions in philosophy, broad enough to accommodate Wittgenstein, as well as the diverse range of other approaches which are now emerging, and will no doubt be added to in future.

None of this is intended to diminish the importance of Elliott's book, which both reflects as well as being an important contribution to, this ongoing debate. If work such as Elliott's gains the prominence it deserves it will signal the end of the worst features of bioethics, by demonstrating the central importance of a more reflective encounter between medicine and philosophy. The individual chapters are themselves full of imaginative observations relevant to the particular issues selected, for example organ donation and drug treatment for depression. Also it is part of Elliott's argument that too much work in philosophy is either trivial or unnecessarily technical or both, and this book is neither of these. It should be required reading both for health care professionals who have an interest in ethics, and for all those professionally engaged in bioethics and the philosophy of medicine.

DAVID GREAVES

*Centre for Philosophy and Health Care,
University of Wales Swansea*

Medicine and the Marketplace: the Moral Dimensions of Managed Care

Kenman L Wong, Notre Dame, Indiana, University of Notre Dame Press, 1998, 232 pages, \$32.00

Health care in our society has reached a critical point in its evolution. Numerous articles have decried current approaches to health care reimbursement by focusing on their negative impact on patient relationships. However, few have reflected on the encroaching import of business ethics on these relationships. Kenman Wong's book *Medicine and the Marketplace* is a critical first beginning of this reflection. Wong engages in a comprehensive ethical assessment of managed care and the impact of business ethics on obligations to patients. As Wong rightly observes, the ethical discussions concerning health care and its economics, focus on obligations of physicians not those of institutions or other health care professionals. However, health care institutions are increasingly interposed between the physician and patient and their decisions are based on business ethics. The book begins by reviewing the history of business and medicine. To describe medicine as being free from the world of money is patently wrong. However, there is increased concern about the foundational morality of the current managed care approach to reduce health care expenditures. The tension is that "the traditional 'good' for business has been and continues to be profit, while the 'good' for medicine is the wellbeing of patients".

Wong describes the moral typology of managed care as six ethical views in two categories. Those critical of managed care are: 1) patient-centred purists; 2) market reform purists; 3) explicit rationers, and those in support of managed care are: 4) for-profit managed care champions; 5) non-profit organisational supporters, and 6) cautious managed care supporters. Wong's criticism of each of these approaches is well presented and his discussion illustrates that "a simple dichotomy, for and against managed care, obscures the moral (and practical) issues of the managed care debate".

Wong realises that the answer to limited health care resources cannot

be found in either increasing non-profit organisations or in a reinforcement of the physician's advocacy role. Non-profit organisations have not always been altruistic nor patient-centred and must realise a profit, no different than for-profit institutions. To Wong the differences between for-profit and non-profit are illusory and health care an industry that is "far too complex to be run by missionaries and candy-stripers". However, Wong is not an unrestrained free market champion. "A restrained marketplace is necessary to protect the rights of all parties." The question is how the two, "business and medicine, whose missions apparently follow widely diverging paths", can be integrated effectively.

Wong supports a view of health care business ethics called stakeholder theory. He believes that "a stakeholder approach can be formulated" to support essential values in health care. Wong feels that managed care organisations should be "held to behavioral standards which are consistent with the objectives of service to the community through the provision of quality health care" and correctly observes the tension between the two roles of health care institutions, ie, businesses and delivering health care. However, "adequate moral grounds ... cannot be found in the traditional understanding either of medical or of business ethics. The traditional patient-centered ethic is unrealistic and irresponsible" and he sees hope in an "enlightened stakeholder approach" as an ethical framework to govern the behaviour of managed care organisations.

Although Wong takes a very important first step in an analysis of business ethics in health care, stakeholder theory does not provide the ethical framework he hopes for. It does provide an important first step, ie, identifying stakeholders, however, it does nothing to help rank stakeholder interests, which is the critical tension in health care today. For example, how do we rank the interests of patients against those of the health care institution? Wong's book is a critical and important first step in the debate on managed care and the discussion of business ethics in health care. It should be read by anyone interested in medical ethics.

JOHN F PEPPIN

Center for Bioethics, Pain Management and Medicine, Des Moines, Iowa, USA.

The Goals of Medicine: The Forgotten Issue in Health Care Reform

Edited by Mark J Hanson and Daniel Callahan, Washington, DC, Georgetown University Press, 1999, 239 + xiv pages, \$55 hb.

The dominant theme in health care and its ethics as we move into into the new century looks likely to be how to allocate scarce health care goods fairly. Many ingenious proposals have been devised for determining how to choose between funding service A and service B, how to fix on appropriate levels for funding individual services, and how to decide who will receive a service and to what extent. Yet it would not be controversial to assert that none of these proposals has met with wide acceptance and trust. One of this remarkable book's premises is that the reason for this general failure is that rationing proposals duck the question: "What is medicine for?" To pursue this question seriously is to sail into waters less familiar to Anglo-American readers than those of medical ethics, namely, those of philosophy of medicine. The idea is that by obtaining some (or a better) answer to this question we will be in a much better position to prioritise services, that is to say, to determine which of two services better fulfils the purpose or purposes of medicine.

This strategy has obvious interest. Yet it has an equally obvious difficulty. While medical ethics has by now a relatively stable set of methods and perhaps some results which claim moderate public acceptance, philosophy of medicine is more varied and contentious, both as to method and results. This being so, it might be thought perverse to seek solutions to a problem, even a large and diffuse one, by translating it into a harder one that is still less definite in its scope. The ground-breaking work of Norman Daniels arguably suffers from this defect, in that having determined that needs are the fairest basis for allocating health care, his account of need has defeated attempts to operationalise it.

If one considers the history of medicine, and if one compares the diversity of health care systems and "philosophies", it could be that much of what passes for philosophy of

medicine rests on a confusion between exegesis of the goals of medicine as historically and culturally constructed and the attempt to divine the trans-historical essence of medicine. We think we are doing the latter, when in fact we are generally able to do only the former. This insight has proved very useful in the historiography of science and in political philosophy, and so I think it would prove in the theory of medicine.

This volume reports on a Hastings Center-coordinated international project to devise a core set of goals of health care which would better answer the question: "what is medicine for" in a way that would make health care reform able to proceed along humane and rational lines. The book opens with a description of the project by the editors, and is followed by a consensus statement on the values, and their meaning, of contemporary health care; the description summarises the views of the project participants. This statement is followed by the position papers prepared by each participant group in the project. Participants were drawn from 14 countries, including the UK, the USA, China, Chile, Sweden and Germany. Predictably, most of the papers are American, but the volume is pleasing in not being merely a reflection on the failed Clinton health reforms. However, while careful and interesting consideration is made of the diversity of European views, and of the relations between different medical traditions (notably Western allopathic medicine and Chinese medicine), little attention is paid to the philosophical issues thrown up by medicine in the poor world. This is the only weakness—and it is a considerable one—in the volume. Given that Callahan's critics have often argued that his attempts to place limits on medical need are unwittingly complicit with attempts to limit care given to the poor, this omission is surprising. One cannot, I suggest, have a philosophy of medicine without a political economy to match.

Overall, however, this is a remarkable volume: rich, of high scholarly standard, intriguing, and readable. The strengths of the book—philosophical and cultural sophistication, a clear eye as to the applicability of its proposals, and a strong sense of the historical and political nature of medicine—make it a book which should be read with profit by anyone interested in this area. In particular, it would make a useful textbook for a

graduate seminar on philosophy of medicine or health care reform.

RICHARD ASHCROFT

*Lecturer,
Centre for Ethics in Medicine, University of
Bristol*

The Future of Human Reproduction: Ethics, Choice and Regulation

Edited by John Harris and Soren Holm, Oxford, Clarendon Press, 1998, 254 pages, £35.00.

It is often the case that the subheading of a book is more revealing than its title. *The Future of Human Reproduction* is not really about the future of human reproduction. Apart from John Harris's projections into the future, most of the book is concerned with the present of human reproduction. The subheading, instead, tells us more. Harris and Holm's collection is about choice; about who should decide and why, about whether the state should regulate our choices and even about whether choice is such a desirable thing after all.

This theme fits well into today's debate on medical ethics in general and reproductive ethics in particular. Choice is no longer viewed as necessarily a good thing. Instead, it is often regarded as problematic, bringing with it dilemmas, confusion and even guilt. At the very least, choice means valuing one thing over another. As Jonathan Glover observes in his impressive chapter on eugenics: "As soon as we start choosing at all, we enter a zone of great moral difficulty where there are important boundaries to be drawn".

Many of the contributors to *The Future of Human Reproduction* are quick to observe that, contrary to popular perception, reproductive choice is not universally respected, particularly when reproduction is assisted. Margaret Brazier, for instance, notes that UK legislation governing in vitro fertilisation leaves little room for reproductive autonomy, especially when it comes to access to services. Marie Fox demonstrates how choice in abortion is limited by the law; Simone Bateman Novaes and Tania Salem remind us that frozen gametes are often the property of the clinic; and Harris observes that as far as cloning and gender selection are concerned, reproductive choice is severely limited.

For Harris, this lack of choice is troubling. He argues that our approach

to issues of reproductive ethics should be guided by the principle of procreative autonomy. According to this principle, competent members of society should be left to make their own decisions about how, when and where to reproduce. Only when there is a compelling reason—such as evidence of significant harm—should the state be allowed to intervene in such decision making.

Harris's justification for this principle draws on the writings of Ronald Dworkin, who has argued that procreative autonomy should be regarded as a democratic liberty just as freedom of speech and racial equality are. Dworkin—and Harris—maintain that procreative autonomy is a freedom not just for those who live in societies, such as the United States, with written constitutions, but for anyone living in a democracy.

One suspects, however, that this elegant defence of procreative autonomy would not wash with a number of the other contributors to the book. Marie Fox, for instance, doubts whether choice is such a good thing after all. Fox thinks that "feminism must be prepared to abandon its sacred cows" and accept that the notion of choice has not served women's interests. Choice has made women look self-serving and has encouraged conflict between a woman and her fetus. Fox suggests that the picture of the "selfish, amoral woman produced by choice discourse" means that feminists must change their tack. One course of action might be, Fox argues, to communicate with opponents, rather than demanding things from them.

In the context of fertility treatment, it is often easier to argue for limits upon procreative liberty because of the children that it aims to produce. So, whilst Marie Fox is unconvincing, those contributors who suggest that policy in assisted reproduction should be guided by the interests of the children born, rather than the interests of the parents, have a better case. In their challenging chapter, Bateman Novaes and Salem suggest that assisted conception has modified women's role in reproduction. Such high-tech interventions mean an increased concentration upon the embryo and a weakened role in decision making for the woman having treatment.

Bonnie Steinbock thinks constraints upon reproductive liberty may not be such a bad thing, although she is concerned that such limits are not the preserve of the state. Steinbock

suggests that judges would be acting irresponsibly if they ignored evidence that a child born of, say, surrogacy is likely to be psychologically impaired as a result. After all, she says, “no one is harmed or deprived by not being brought into existence”.

Guido de Vert takes the concern about the welfare of others one stage further. He argues that there are three parties to consider in assisted reproduction: the woman (or couple), the embryo/child and the doctor. According to de Vert, the doctor “has his own responsibility for the consequences of his acts”. He therefore has a duty to consider whether his patients will make good parents and, if he is not convinced of their suitability, to refuse to provide treatment.

The recurrent problem here is evidence. Fisher and Sommerville, in their chapter on postmenopausal women, as well as Steinbock and de Vert, all worry that there is little data showing what harm might be inflicted on children born of assisted reproduction. Such a lack of evidence of harm should, arguably, make these contributors abandon the notion of limited access to assisted reproduction. But they do not. Ultimately, it is only Harris who is prepared to stick by the principle that reproduction should be an autonomous activity, free from outside interference unless a significant chance of serious harm can be demonstrated in advance.

In his introduction, John Harris suggests that the eclectic group of contributors to the volume reflect the central theme of choice. An extension of that theme might be to choose to read the book or to choose not to. From my point of view, however, reading it is the right choice to make.

JULIET TIZZARD

Director, Progress Educational Trust, London

Truth and the Child 10 years on: Information Exchange in Donor Assisted Conception

Edited by Eric Blyth, Marilyn Crawshaw and Jennifer Speirs, Birmingham, British Association of Social Workers, 1998, 83 pages, £5.95.

The original *Truth and the Child* was published in 1988 after publication of

the Warnock Report, which identified issues arising from the increasing use of human reproductive technologies. The authors of the original collection felt that the rights of children to information about their origins had not been addressed satisfactorily by the committee chaired by Warnock, which indeed supported a policy of donor anonymity. This policy of anonymity was incorporated into the Human Fertilisation and Embryology Act (1990). Ten years on, this new collection revisits the issue, offering powerful arguments, anecdotes, and some research supporting the authors' position that with regards to information about origin the interests of the children created by donor insemination should take precedence over those of their infertile parents or the gamete donors who enabled their creation.

We have learned from the practice of adoption that for some people knowledge about their biological origins is crucially important if they are to have a strong sense of their own identity. Every day it becomes clearer that knowledge of family medical history, including genetic information, may be necessary during one's life in order to make choices about one's own health, medical care, and decisions to procreate. Current practice—and legislation from most countries, as reviewed in the appendix of this book—supports parents in secrecy, not just about the identity of the donor, but about the very fact that the child was created with donated gametes.

The interdisciplinarity of the authors of the various essays in *Truth and the Child* contributes to the success of this book, which is published by the British Association of Social Workers. Contributors include an anthropologist, a paediatrician, a sociologist, a psychiatrist, a clinical geneticist, social workers, and academic lawyers. Very interesting and valuable are contributions from a family with two adopted children; from two “donor offspring”; from an egg donor; from a mother of children conceived by donor insemination, and from a mother of twins born following a surrogacy arrangement. These are voices often left out of the medical and ethical discussions of these issues.

The arguments presented by the contributors all lead to the same con-

clusion: children should have complete information about their biological origins. Some of the arguments in favour of this stance are:

The children will find out anyway, either inadvertently from a family member or friend, or in the course of their lives through the health care system, especially with the increased use of genetic testing; those writing as “donor offspring” report sensing that something was different in their families (for example family resemblances and circumstances of one's birth are never mentioned).

The children have a right to know—several authors refer to the section in the United Nations Convention on the Rights of the Child which claims for children the right to a name, nationality, knowledge of parents, and right to preserve one's identity.

It is damaging to family relationships to begin and exist on a foundation of dishonesty. Stigmas attached to these practices are thus reinforced and perpetuated. Practices in other countries, and data from Sweden, suggest that there should be little difficulty recruiting gamete donors who are willing to be identified. This addresses the main argument against total openness, which is that no one would be willing to donate.

This is just a sampling of the arguments presented in this work; others are grounded in the contributor's discipline or personal circumstances. That this book manages to present this wide variety of perspectives in less than 100 pages is to its credit and the editors should be congratulated for the consistent quality of all contributions.

How powerful are the arguments presented in *Truth and the Child*? Very powerful indeed, if we may judge from the fact that the British government has recently announced plans to change the law guaranteeing donor anonymity and thus conferring on children conceived with donated gametes the right (once they become adults) to trace the donor.

CHRISTINE HARRISON

Department of Pediatrics and Joint Centre for Bioethics, University of Toronto, and Bioethics Department, The Hospital for Sick Children, Toronto