



# Reviews

Edited by Ian Buchanan

## REVIEW ARTICLE

### Outcome Assessment: Time for Reflection

Twenty years ago Cochrane pointed out that the majority of medical treatments were based less upon empirical data than upon tradition and 'accepted wisdom'.<sup>1</sup> Since that time the concept of outcome assessment has grown, especially in relation to health services provision. In fact, some variant of outcome assessment now appears in a wide variety of health and medical settings, under such guises as medical audit and 'quality of care'.

Because the single term 'outcome' is used in a variety of health care situations there has been a tendency to conclude that all 'outcomes' are of the same kind and can be measured in similar ways. However, there are enormous differences between interventions such as drug treatment, surgery, nursing care, community psychiatry, health promotion and public health initiatives. Since all outcomes must be related to the nature of the intervention—and might include such diverse results as death, wound healing, return to work, alleviation of suffering, improved health status or improved quality of life, the measurement of these aspects of outcome is profoundly problematic—not least because of the difficulty of conceptualisation. Moreover, those outcomes which are reflective of a medical model clearly inhabit a different universe of discourse from those which are related to psychosocial experience. Nevertheless, there is a tendency to treat all these areas as if they were of the same order.

Most outcome measures which purport to gather the views of patients are implicitly modelled upon clinical values, even though they contain items of a social or emotional nature. For example, many questionnaires contain items on social and physical 'function' which are founded on some notion of the capabilities and predilections of 'normal' persons. In fact such items are laden with social, cultural, and often moral values. This situation is very different from a clinical approach where 'normal' values may be available in the form of average blood pressure or sodium/potassium ratios, or the average time a particular type of wound takes to heal. But it is a very different matter to assume a 'normal' health status or 'normal' quality of life.

In addition, the content of most measures which purport to assess outcome from the patient's point of view do no more than use consumers as sources of information about aspects of health care which have been predetermined by researchers. True stories of consumer needs, satisfaction or quality of life would have to identify and assess the criteria for outcome of relevance to patients, not only to researchers, doctors, nurses or health promoters.

This raises further questions. Where a number of outcomes have been assessed which include both clinical and patient-defined parameters, and where the clinician is satisfied but the patient is not, whose view will prevail and by what means will such discrepancies be addressed? Furthermore, all those concerned in outcome studies have different interests and thus constitute different audiences; policy-makers, doctors, economists, patients and administrators. There is likely to be a huge gap between the collection of data, and willingness to act on the results of the research.

Timing is a further important consideration, but its significance is often neglected. At what point can an outcome be considered to be an outcome rather than part of a continuing process? Differences in the timing of measurements may result in very different judgements about the same intervention. In addition, outcome assessment is likely to suffer 'technical fragmentation',<sup>2</sup> where aspects of a whole are broken off into professionally manageable portions.

Outcome measurement in the health services field is characterised by unsystematic, ill-defined and uncoordinated studies. It is unfortunate that outcome assessment appeals to all sides of the political spectrum; from those who wish to see more consumer input and to listen to the voices of patients, to those who want to create the illusion of providing 'value for money' in the medical marketplace. Where some activity is acceptable to all parties concerned it is more likely to pass unexamined. However, not to investigate the nature of outcome assessment is to encourage not only poor research but also the misguided notion that the voice of the consumer is indeed being heard in the land.

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## References

1. Cochrane, A. (1972). *Effectiveness and Efficiency: Random Reflection on Health Services*, Nuffield Provincial Hospitals Trust, London.
2. Manning, N. (1985). *Social Problems and Welfare Ideology*, Gower, London.

## BOOK REVIEWS

**Unfinished Business: What Happened to the Cartwright Report?** Edited by Sandra Coney, 1993, Women's Health Action, Auckland, New Zealand, ISBN 0-473-02018-1, 192 pages, NZ\$29.95.

Coney's *Unfinished Business* is a collection of essays on the aftermath of the 'unfortunate experiment at National Women's Hospital'. The 'unfortunate experiment' refers to Professor G. H. Green's research programme, set up in 1966 at the National Women's Hospital, Auckland, New Zealand, to discover whether or not carcinoma *in situ* of the cervix leads inevitably to invasive cervical cancer. Over a period of more than 20 years women, ignorant of the fact that they were in a research programme, were monitored but given no treatment. In June 1987, Phillida Bunkle and Sandra Coney published an article in *Metro* magazine describing the research, which the then Minister of Health responded to by setting up a judicial inquiry, headed by Judge Silvia Cartwright.

*Unfinished Business* starts with a helpful chronology of events related to the Cartwright Report from 1987 to 1993. The first chapter, written by Coney, gives a summary of the main issues which are later covered in more detail by a number of different writers, amongst them Phillida Bunkle, Lynda Williams (the first patient advocate at the National Women's Hospital) and Helen Clark (Minister of Health in the Fourth Labour Government and now leader of the New Zealand Labour Party). In this way topics such as patient advocacy, the formation and performance of ethics committees and the efforts to establish treatment protocols are covered in brief at the beginning of the book before being more thoroughly examined in the body of the text.

The overall emotional tone of the book seems to be one of disappointment and resentment. The disappointment appears to come from a perceived, as well as an actual lack of progress towards the goal—the implementation of Judge Cartwright's recommendations *in toto*. The resentment is apparent in the reasons given for lack of progress. At their most extreme these give the book a lack of balance. For example, Coney's insistence that the 'over-riding concern of doctors is the need to cooperate in order to protect mutual interests' and Debbie Payne's 'the reasons for the opposition' (to treatment protocols) is that 'they threaten medical autonomy', demonstrate an unwillingness to look further than medical arrogance and 'rank-closing' to explain lack of action. Yet to less emotionally involved commentators there will appear to be many contributing causes.

The book offers some interesting additions to the continuing debate about informed consent. Informed consent was to be at the heart of the New Zealand Code of Health Consumers' Rights, yet even the choice of practitioner can be severely limited. In a country the size of New Zealand, where there are often only one or two specialists in the increasingly complex fields of medical treatment, the 'if you don't like it shop elsewhere theory of consumer sovereignty' has a hollow ring, as Bunkle points out in her section on 'market-place medicine'.

Do the authors mention any good outcomes from their years of struggle? Occasionally. Even though Bunkle appears even more dispirited than Coney (she begins her chapter 'I am wondering what to write ... Wondering if it is worth writing anything at all ...'), she does acknowledge that 'we were successful in bringing about a change in consciousness'. And Coney concludes 'The major positive change to occur ... has been attitudinal'. Most New Zealanders working within the health system would probably agree with that part of her analysis which says 'Health care consumers have become more assertive and aware of their rights, and health professionals' awareness of issues such as informed consent has been heightened. Patients are more likely to be offered information to (help them) make decisions, and they feel more able to ask questions, and have them answered'.

It is indeed likely that changes in attitude will prove the real and permanent value of the Inquiry. Of course knowledge will continue to equal power, and nowhere more so than in the professions, including medicine. But part of the legacy of the Inquiry is a generation of medical students (50% women) amongst whom are some determined to carry on in the direction set by Cartwright.

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### Essential Public Health Medicine

R. J. Donaldson and L. J. Donaldson, 1993, Kluwer Academic Publishers, Lancaster, ISBN 0-7923-8826-7, 514 pages, paperback, £19.95.

In many ways, as the authors point out in their introduction, this is the second edition of the established textbook *Essential Community Medicine*, though extensive rewriting and updating mean that, in reality, an entirely new book has emerged.

*Essential Public Health Medicine* is remarkable in managing to keep abreast of an extremely diverse and rapidly changing subject. The book is both wide-ranging and up to date, and covers most topics in considerable depth.

The first three chapters alone address a startling range of issues relating to information on health status, the sources and uses of health-related data, basic epidemiological principles, approaches to problem solving in the real world of health services, and current

thinking in health promotion. All the information presented in examples and diagrams relates to the UK, though of course many of the issues are easily generalisable to other countries.

The fourth chapter is more resolutely UK-specific, being a Cook's tour of the British NHS and social services. The 1991 reforms of the health service and the subsequent community care changes are discussed, if a little uncritically. There is also a helpful introduction to questions of quality measurement and improvement in health services.

The six remaining chapters, comprising about half of the book, focus on the specific issues of physical disability, maternal and child health, mental health, the elderly, communicable diseases, and the environment, approached from a public health perspective. All present current policy issues and existing services in a clear and easily digestible way, and are bristling with useful facts and figures. Presumably these particular topics are chosen for the particular public health challenges they present.

Throughout, there is a tendency for information to be presented in a matter-of-fact way which lacks (or avoids) a critical or questioning edge. For instance, although specific health issues relating to black and ethnic minority populations appear at various points, there is no discussion of the impact of racism on health and health services. Although cigarette smoking is acknowledged as the commonest preventable cause of death in Britain, there is little exploration of why effective tobacco control measures have not been forthcoming. The increasingly important issue of social class inequalities in health merits less than four pages, and tends to discount the significance of economic policy as a contributory factor. In general, the notion that improving the public health requires political action at many levels is absent.

Nonetheless, this is a clear, comprehensive and readable textbook, which should provide almost all the public health material which medical students and other health professionals in training need. It can also be recommended to public health specialists in their first year of postgraduate training.

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**Life and Death: Philosophical Essays in Biomedical Ethics** Dan W. Brock, 1993, Cambridge University Press, Cambridge, ISBN 0-521-41785-6, 435 pages, hardback £42.50; ISBN 0-521-42833-5, paperback £14.95.

These days it seems that almost anyone who has ever felt that something just wasn't right is a bioethicist. Thus, for those who dislike intellectual exercise but nonetheless prefer to feel informed and concerned, there is a wide range of literature available to pass trivial comment on matters of importance.

Such readers should be warned that, despite its at-

tractive title, Dan Brock's book is not for them. It is a serious attempt by an analytical philosopher to make sense of the subject conventionally called medical ethics or 'bioethics' and, while I find much to disagree with in Brock's work, this consistent and thoughtful contribution to the field must surely be warmly welcomed.

The book is a compilation of essays written over a number of years, and although each essay is capable of standing alone they do fit together rather well to form a comprehensive and coherent discussion. Brock divides the book into three parts. The essays in Part I address questions fundamental to medical ethics, about the aims of medicine and the nature of the doctor-patient relationship. Brock provides a clarification and defence of the doctrine of informed consent, in the process discussing foundational questions about the nature of morality and rational thought.

Parts II and III address some of the specific issues that form the subject matter of most books on medical ethics, such as justified killing, the value of prolonging human life, the allocation of scarce life-saving resources, and the rights of the elderly. Part II concerns such 'life and death' issues as they face clinicians in practice. Brock demonstrates the confused nature of the thinking behind the view that there is a morally significant distinction between killing and allowing to die. He provides a defence of voluntary active euthanasia and argues that clinicians may justifiably kill incompetent patients under certain conditions. Part III concerns questions facing policy-makers, and here Brock defends an approach to rationing based on the concept of the 'Quality Adjusted Life Year'. He attempts to spell out his conception of 'quality' or 'the good life', and to draw out the implications of his view for the distribution of health care resources to such groups as the rich and the poor, the young and the old.

What makes these discussions philosophically valuable is the fact that they are grounded in a clearly explained position in first order moral philosophy, which is itself grounded in the conclusions of Part I concerning the nature of moral thinking. Even if we reject the underlying assumptions in ethics and metaethics, it is interesting to see their implications so clearly and thoroughly worked out. Brock is massively influenced by the work of John Rawls, so much so that he at one point describes the Rawlsian view in metaethics as 'the current philosophical view', apparently momentarily forgetting that there are other views about metaethics currently held by philosophers besides those of Rawls. Brock defends a rights-based position in moral philosophy which is grounded in the Rawlsian 'reflective equilibrium' account of moral thinking.

On that account of the good, human beings are seen primarily as autonomous agents, and just as, in Rawlsian social theory, there are certain 'primary social goods' which a just society must provide for all citizens, so in Brock's bioethical analogue of Rawls' theory there are certain 'primary functional capacities' which must be maintained for all persons, if those persons are to live a good life. These capacities constitute the objective

component of the good, since they are necessary features of any good life. However, there is a substantial subjective component to the good life in that, exercising these fundamental capacities, people may choose to pursue a wide variety of life-plans which fit their personal 'conceptions of the good'.

The Rawlsian influence brings with it not only the undoubted advantages of that approach to philosophy, but also its disadvantages. Like Rawls, Brock has an overly rationalistic view of life and what makes it valuable. Much rests on appeals to what are thought to be the considered intuitive responses of 'most people', or most 'reasonable' people. This approach ignores the fact that, unless one takes far too restrictive a conception of a 'reasonable person', what most reasonable people would say on a particular issue depends largely on how they are feeling at the time, and how the issues are presented to them. (Few people in fact attempt to reach reflective equilibrium, and who knows what they would come up with if they did.)

Such problems aside, Brock's is an impressive work. Those who read the book right through may perhaps think there should be slightly less repetition of arguments and examples, with correspondingly more cross-referencing, while those who wish to pick out specific essays to read will welcome the self-contained nature of each one. For those in the latter group, Brock provides an excellent introduction which précis the arguments of each essay and gives a fuller overview of the whole book than I can give here.

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#### **The Ethics and Politics of Human Experimentation**

Paul M. McNeill, 1993, Cambridge University Press, Cambridge, ISBN 0-521-41627-2, 315 pages, hardback £35.00.

The agenda of traditional medical ethics has been heavily criticised for ignoring the political context in which the decisions it discusses are actually made. This comprehensive and closely argued study of medical experimentation on human subjects shows something of the way forward. McNeill's thesis is that human experimentation is as much a political as an ethical issue involving the balancing of groups of interests within the contexts of particular institutions. Consequently, philosophical analysis of the ethics of human experimentation cannot be carried out in isolation from an understanding of the history and practice of the institutional mechanisms that make the decisions.

Part I offers a brief history of unethical experimentation and the development of ethical codes. McNeill offers a sane analysis of the rôle of codes of ethics, making clear their limits: the first comprehensive code—the German Richtlinien of 1931—did nothing to prevent the abominations of Nazi doctors and scientists. Part II traces the international history and character of research ethics committees, presenting and

summarising a number of empirical surveys. Part III discusses the ethical and legal background and Part IV examines the political context of research ethics committees concluding in workable recommendations for their structure and practice.

McNeill shows that the primary mechanism for making decisions about the ethics of proposed research is the research ethics committee. He argues that these committees are seriously flawed. They focus too narrowly on research proposals rather than research practice, and, within proposals, on the issue of consent, rather than the interests of subjects understood more generally. McNeill's most damning criticism concerns the composition of committees. Except for Denmark and New Zealand, committees are composed largely of medical professionals with 'lay members' a small minority. In theory, these committees are a sensible mix of scientific expertise and common sense. In reality, they are an unequal contest between the mass of research interests and a few non-professionals, who are mostly overawed by the expertise that surrounds them, unclear about their rôles and reluctant to make seemingly vague and unsupported 'value judgements'. In order to make the covert political character of the process explicit, he proposes a 'democratic' model in which smaller, tighter committees are equally composed of representatives of researchers and representatives of subjects. Provided with greater administrative and expert support, ethical committees could be much more effective in tackling their proper tasks. McNeill is admirably robust in his insistence that ethical committees are not just another means of vetting the scientific validity of proposed research; their job *is* to make and support vague judgements about research practice.

McNeill's focus is almost exclusively on the rôle of ethical research committees. Despite his reservations about the over-concentration on issues of consent, it would have added to the usefulness of the book as a reference text to have included some parallel account of the ways in which subject consent is sought and respected. Patients need the support of advocates not just on committees but in the offices and wards of our medical institutions.

Still, this is a seminal contribution to medical ethics. It makes clear that if ethical committees are to meet their obligations, they need to take a close look at the ethics of their own practice. Reading this book would make a fine beginning.

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#### **CONFERENCE REPORT**

##### **International Bioethics Seminar, Dunedin, New Zealand**

The University of Otago Bioethics Research Centre held a week-long international bioethics seminar in the last week of November 1993. Keynote papers were pre-

sented by 17 members of the International Association of Bioethics, lured to Dunedin for an IAB board meeting.

The first part of the seminar programme was devoted to classic dilemmas in medical ethics. Bioethics is sometimes criticised for focusing on extreme cases—'Do we withdraw ventilator support?', 'Should the baby live?', 'Does a doctor have a duty to warn third parties that a patient is HIV positive?'. Inevitably, the contextual detail of actual cases is sacrificed in posing neatly packaged problems for instant solution by panels of experts. However, it is interesting to see the differing approaches of health professionals, lawyers, philosophers and patients to clinical dilemmas, particularly when the expert panellists come from a range of countries and cultures. A session on STDs and AIDS, for example, highlighted cultural differences in relation to confidentiality. Lengthy debate about patient confidentiality or consent to HIV testing of surgical patients is a luxury that many African and Asian countries cannot afford in the face of the AIDS pandemic, and the emphasis on hard cases is a red herring for them.

Several conference sessions considered the ethical problems posed by dramatic advances in medical technology. In his closing address, noted US academic lawyer Alex Capron posed the question 'Do biomedical advances threaten human rights?'. Using illustrations from the use of IVF, genetic screening for Huntington's disease, HIV testing, and treatment of ICU patients, Professor Capron argued that thousands of patients benefit from new technology. But such developments may be 'a bane and not just a boon', leading to the commodification of human beings ('Are frozen embryos property?'), discrimination and invasion or privacy ('Who has access to genetic information?') and a technological imperative whereby life-sustaining treatments are administered to patients whose prospective quality of life is very poor. Capron pointed out that bioethicists have embraced the language of rights, for example to self-determination and information, as a natural response to the vulnerability of patients in the face of biomedical advances. But he argued that disease, rather than physician malevolence, is the true cause of such vulnerability. Although safeguards such as the doctrine of informed consent and ethics committees have an important role to play, they are more effective in controlling the process of biomedical research than in regulating outcomes.

Overseas participants were clearly interested in the role that ethics committees have played in New Zealand following the Cervical Cancer Inquiry (see also the review by Val Grant in this issue of *Health Care Analysis*), and intrigued by the high degree of lay involvement. Otago bioethicist Professor Alastair Campbell stated that 'the system in New Zealand is remarkable in world terms'. However, Dunedin epidemiologist Professor Mark Elwood decried the time and cost involved in getting ethical approval, especially for multi-centred trials, and stressed the importance of 'dialogue rather than dictatorship' in reviewing medical research, a

view hotly disputed by the members of local research committees present at the conference.

The idea of an 'ethics of care' has become popular over the past decade, as feminists and teachers of nursing ethics have argued that impartially grounded ethics—most obviously the oft-cited Beauchamp and Childress principles of autonomy, beneficence, non-maleficence and justice—may fail to take into account the truly significant features of individual cases. Several commentators at the conference cited nursing practice as evidence of a more reflective and eclectic approach to the solution of bioethical dilemmas. Auckland philosopher Jan Crosthwaite referred to the emergence of a distinctively feminine health care ethic, with an emphasis on nurturing and an empathetic awareness of patients' needs and relationships. The risk, as Dr Crosthwaite herself pointed out, is that women will be reaffirmed in their traditional roles of carers and nurturers. There is also a danger, adverted to by Australian philosophers Helga Kuhse and Peter Singer, that in the wholesale rejection of the principles approach to bioethics we may 'throw the baby out with the bath water'. Care may be necessary but not sufficient for ethics.

The final two days of the conference were largely devoted to the apparently intractable issues of resource allocation and markets for health services. Professor Dan Wikler provided a fascinating analysis of the Clinton health care reforms in the USA, noting that rationing has effectively been eschewed at a federal level, and citing the Oregon plan as a courageous (albeit flawed) attempt by an individual state to ration limited resources. Highly critical of the Clintons' endorsement of managed competition, he argued that a single-payer system such as Canada's would have been preferable, but was unacceptable to the politically powerful medical and insurance lobby groups.

Speaking of the British experience, Dr Raanan Gillon saw rationing as inevitable, whether a country spends 6% of GDP on health care (UK) or 14% (US). Compatriot philosopher John Harris argued that real and present medical dangers should be met with a greater share of public monies than future and speculative defence worries.

The sobering experience of Hungary was related by medical ethicist Dr Bela Blasszauer. Hungary leads worldwide mortality figures for several diseases (and for suicide) and in a 'free' health care system, bribes are endemic. Only 4.5% of GDP is spent on health yet there is appalling waste of medical resources, and patients are starved of information about topical health issues by a powerful medical establishment.

In relation to New Zealand, Irihapeti Ramsden lamented the 'normalisation of poor health status for Maori'. She emphasised the importance of epidemiological data to make the case for priority funding of Maori health needs, sensitivity to Maori concerns about organ transplantation and post-mortem use of body parts, and the need for greater Maori representation on local ethics committees.

Overall the Otago Bioethics Research Centre is to be congratulated for providing a rich and varied inter-

national seminar, justifiably described as 'New Zealand's bioethics event of the decade'. Yet some participants may have been left with the impression that bioethics is becoming a fashionable and cosy club where 'experts' debate philosophical issues. One of the most stimulating conference addresses was given by Auckland University's David Seedhouse, who argued that bioethical inquiry is seldom critical of the context in which health care delivery occurs. Bioethicists tend to act as the handmaidens of modern medicine, rather than challenging the socio-political context in which decisions are made. There continues to be a need expressed by health practitioners for guidance in difficult situations and, in order to give assistance and yet be accepted by the medical establishment, bioethicists are forced to accept most of the premises which underpin the medical system. However, by 'playing the game', they may mislead the public into thinking that 'medicine must be becoming more ethical because there is so much more discussion of medical ethics' and may divert attention from the much more serious and powerful games being played elsewhere.

Dr Seedhouse's remarks are a timely warning to bioethicists not to be co-opted into the health care systems which it is their role to critique. The Inter-

national Bioethics Association has an important role to play in promoting bioethical debate, teaching and research worldwide, particularly in countries where public discussion of such issues is muted. For individual bioethicists, the challenge is to be what Dr Blasszauer called 'the voice of the voiceless'.

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### **Review Editor's Note**

We hope to make 'Retro Review' a regular feature of the Reviews section. 'Retro Review' will feature books or papers published in earlier years which remain of contemporary relevance and which, in the opinion of the reviewer, are worth a revisit. Potential contributors are very welcome to contact the Reviews Editor, who will also be pleased to consider commentaries on reviews already published, or ideas for Review Articles.