

## Book reviews

### Medical Research with Children: Ethics, Law and Practice

Richard H Nicholson, editor,  
265 pages, Oxford, New York, £12.50,  
Oxford University Press, 1986

This book is the report of a working party of the Institute of Medical Ethics, whose three-year remit was to consider the moral questions related to clinical research involving child, reviewing the moral basis and identifying acceptable moral criteria, in an attempt to draw up guidelines for researchers and ethics committees.

The book is written in a concise fashion which successfully avoids endless woven moral/legal arguments which could have shrouded the important points of concern. I was also relieved that overt condemnatory statements were avoided and that the authors allowed the description of the research projects given as examples to stand as sufficient witness. This style, and the sheer number of research projects used as illustrations, make the book very readable because it actively involves the reader. The layout of the chapters is also helpful. However, the lack of standardisation throughout the chapters in the citing of references is a problem. For example, the chapter on children and the law uses a different (and, to me, confusing) method of abbreviations – possibly a lawyer's attempt to expose doctors to the annoyance of not understanding another profession's jargon!

The introductory chapter sets the scene for the apparent need for further guidelines in research involving children. It lists the guidelines already suggested by authorities. It reviews the history of surveillance (or lack of it) in the past and outlines the present moral dilemmas. It concludes with the aims

and working methods of the working group. The second chapter concentrates on the definitions and thus avoids linguistic confusion in the later discussion. The potential dryness of the definitions is offset by the liberal use of examples. The chapter on child health and the scope of research is helpful in putting the strides made by science into a fair perspective. It also explores the degree of physical intervention and the value of using appropriate statistical analysis, not only as a way of maximising the scientific value of a research project, but also as a way of avoiding unnecessary risk by stopping the project when a statistical result is obtained. The example given of the avoidability of retrolental fibroplasia (blindness associated with oxygen administration to preterm babies) if sequential statistical analysis had been used is very apt. Non-medical research is also covered, mainly in the fields of nursing and education. The difference between therapeutic and non-therapeutic research is also emphasised.

The chapter on the structure of the argument concentrates on the moral philosophical background. I found this helpful in understanding more about the difference between the pluralist intuitive approach of the deontologist, and the more critical consensus-based utilitarian method. I found the following sentence a refreshing compromise: 'It is perfectly self-consistent for him (a sophisticated utilitarian) to recognise the utilitarian basis of all thinking, but to recognise also that this itself requires him, when considering practical proposals, to be guided by firm principles (of the same sort as the deontologist has adopted for his own kind of reason), because that is the most likely way, on the whole, of acting for the best'.

The chapter on risks and benefits covers analysis of risk – identification, estimation, evaluation – and also defines benefit. The illustrations used

are helpful and entertaining (for example the equivalence of the one in a million risk of death following the smoking of three quarters of a cigarette, with one-and-a-half minutes of rock climbing, and with six minutes of canoeing). The medical procedures such as blood sampling, lumbar puncture, liver biopsy, are reviewed in terms of risk, and the mathematical assessment of disutility illustrated. The definitions – of negligible, minimal, and more than minimal risks – are contrasted between the British Paediatric Association and USA guidelines. The chapter on children and the law covers who may consent, and to what, within the existing law of England and Wales. It underlines the existing hazy state of the law, suggests how a child's advocate might help, and leads neatly into the chapter on whether children can permit research. This reviews the literature on the development of a child's knowledge of the body and the ability to make moral judgements. It concludes that at a developmental age of greater than seven years there should be an attempt to obtain the child's consent and that as the child approaches the age of fourteen years, so the necessity for his/her consent increases.

The history and functioning of ethical committees based partly on existing literature, but mainly on the working party's own research, using a questionnaire, is reported. Two hundred and fifty-four ethics committees were identified and 174 questionnaires were returned and used for the analysis. This chapter provides a useful source of reference.

The chapter on conduct of research is a useful *aide-memoire* to the planning and presentation of research protocols. It illustrates the difficulty in obtaining informed consent for innovative therapy at times of urgency such as immediately after the birth of a sick preterm baby.

The summary and conclusions are a list of the working group's recommendations derived from their discussions outlined in the preceding chapters. These include the need for scientific soundness, quantification of risks versus benefits, limitations of non-therapeutic research to situations of minimal risk and parent and child consent issues. Draft rules for ethics committee organisation are also presented.

Obviously there are areas of controversy which will exercise those interested for many years. However, this report, as a distillation of so many man-hours of experienced thought, will act as a point of reference and balance in the tension between doing no harm to individual children and avoiding hindering essential research for the good of many children. In my opinion this book should be considered as essential reading for those who perform or supervise research involving children and for those who serve on ethics committees.

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## The Healing Arts: A Journey Through the Faces of Medicine

Ted Kaptchuk and Michael Croucher, 175 pages, London, £5.25, British Broadcasting Corporation, 1986.

The BBC published this book to accompany one of its major television series. I had not seen any of the episodes before writing this review, but the book is certainly readable in its own right.

It is written for the lay public but could well inform medical students and other aspiring health professionals who are generally taught little about the history of their own medical heritage, let alone how it compares and contrasts with that of other systems of medicine. It starts with a fairly objective if somewhat over-simple account of the philosophical bases of the major systems of healing and of some of the specific practices which are widely in use in the world today. It argues that, in its origins, the dominant system in the West – scientific medicine – was based on Greek thought, and had much in common with the systems still widely practised in China and India. It suggests that, although Western medicine has achieved much by its discovery of the

part played by micro-organisms in disease and of methods to defeat them, it could achieve far more were it to acknowledge openly the ideas, still inherent in Eastern theories of illness, namely that ill-health is essentially a loss of balance and that the process of healing consists of restoring that balance.

In essence, the book is a plea to Western practitioners and patients to regard what is still likely to be dubbed 'fringe' medicine as 'complementary' rather than 'alternative'. Kaptchuk, who is responsible for the content of most of the book, trained in both Western and traditional Chinese medicine. He now directs a Pain and Stress Relief Clinic in Boston, USA. The large, eclectically-minded staff offer any one of 22 different regimens to those whose pain has not been satisfactorily controlled by orthodox Western medicine. He argues that effective therapy in every system of medicine is dependent upon the performance of rituals by the healers. The rituals vary from system to system, but they all work as magic does, that is by altering the perceptions people have of specific phenomena. In the case of healing, the sufferers have to perceive themselves as capable of overcoming forces responsible for their pain by strengthening the agents working to restore their balance. The imagery required to do that will depend upon the cultural heritage and assumptions of the sufferers.

The examples he chooses to illustrate his argument are drawn from many kinds of therapeutic situation. They include such diverse instances as the shaman's involvement of relatives in the treatment of illness among the Samoyed tribe in Arctic Siberia, the Simonton's 'guided imagery' fantasising techniques in cancer therapy in Dallas, Texas, and, in another Westernised setting, the effect of prescribing by an authoritative figure as compared to someone of lesser status. In each instance, it is fair to conclude that the healing occurred as a result of the sufferer's changed perception.

The message which the book sets out is not a new one, but it is elegantly stated and persuasive. Reviewing the book for the *Journal of Medical Ethics* it is appropriate to ask whether it raises any ethical issues. The authors do not suggest that ethical issues are raised when practitioners of scientific medicine refer their patients to practitioners of complementary healing procedures. Indeed, they advocate conventions of sorcerers and scientists!

Since most of the therapies are likely to be a good deal less invasive and potentially lethal than those with which orthodox medicine is frequently involved, it may be thought that ethical issues are not likely to arise. But it is pertinent to ask whether the conduct of doctors who seek to discourage patients from consulting practitioners, who are prepared to try to give them the help (the magic) which they are not receiving from orthodox methods, is ethical or unethical. Doctors are sometimes inclined to claim that they are protecting their patients from quacks. It is not always easy to accept that other healing rituals may be as or more effective than those which have become standard practice in the Western system of scientific medicine. This book may help that acceptance.

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## Madness and reason

Jennifer Radden, 174 pages, London, £5.95 paperback, George Allen and Unwin, 1985.

'Bad or mad' we say – so madness is an excuse for wrongdoing. Ms Radden is concerned with why this should be so. Consider the following syllogism:

'Peter is not responsible for his being mad.  
If Peter had not been mad he would not have killed Paul.  
Therefore Peter is not responsible for killing Paul.'

Ms Radden calls this argument the 'medical model' and demonstrates that it is false. The following counter-example shows why:

'Peter is not responsible for Paul calling him a fool.  
If Peter had not been called a fool he would not have killed Paul.  
Therefore Peter is not responsible for killing Paul.'

Ms Radden, therefore, rejects the idea that we may excuse a wrong act simply because it is caused by illness. For her it is the effect of the madness on reasoning that is crucial. The question is not 'is he ill?', but 'how can he reason about the act'? And there are only two key factors which underlie the excuse: *ignorance* and *compulsion*. If the madness is such that the person is ignorant of why or how he acts, or if he is compelled to act,