Teaching Genetics to Medical Students

Working party of the Committee on Clinical Genetics of the Royal College of Physicians, 32 pages, London, £5.00, Royal College of Physicians, 1990

The last few years have seen a rapid expansion in knowledge about genetic factors in disease, and also the introduction of many new genetic technologies of actual or potential clinical relevance. The process shows no sign of slowing down, so this report, produced by a Working Party of the Committee on Clinical Genetics of the Royal Physicians of London, is timely. The report is short and succinct, and its message is clear.

The report reviews current medical undergraduate teaching in genetics at different centres in Britain. Only a small amount of timetabled teaching time is allotted to genetics, the average being a total of around 20 hours during the five-year curriculum. There was wide variation between centres on both the course content and the teaching time, but in almost all medical schools the majority of the genetics teaching formed part of the pre-clinical course.

While recognising that the medical undergraduate curriculum is already overcrowded, the working party concluded that there was an unambiguous and pressing need for the establishment of carefully co-ordinated and clearly delineated genetics teaching in medical schools. They go on to define topics for pre-clinical genetics teaching, and make strong recommendations for strengthening and co-coordinating genetics teaching during the clinical course. A draft syllabus and suggested teaching methods for the clinical course are given in an appendix.

If there is to be more and better teaching, there will need to be an expansion in the numbers of clinical genetics teachers. The report concludes by recommending a task force should be set up to accelerate the pace of change in genetic education.

The introduction of both genetic screening and new technologies has already highlighted many ethical problems. If gene therapy becomes a practical possibility there will be new ethical issues to consider. It was pleasing to see that in a survey of clinicians an appreciation of the major ethical issues in medical genetics and an awareness of the stress caused in families by genetic disease were ranked highly as skills that needed to be taught to clinical students.

Reports are not self-executive. The next steps are awaited with interest.

A Casebook of Medical Ethics

T F Ackerman and C Strong, 240 pages, New York, £32.00, Oxford University Press, 1989

This book consists of a series of medical case histories which can be considered and discussed. The cases were chosen because they posed difficult moral problems for the doctors involved to consider in deciding how to act in managing each case. Every case description contains a wealth of detail, including many of the complexities of the patient's personal circumstances and a full account of the medical issues involved. Almost all are actual cases of which the authors have personal knowledge.

The cases are grouped together into chapters with a common theme, covering the topics of paternalism, duties to the patient and the family, making decisions for others, medical research, and doctors and third parties. As well as the case histories, there is a commentary at the end of each chapter which provides guidance on the moral principles involved in the cases.

None of the case histories given are straightforward, either from a medical or a moral perspective. It is fortunate that in practice not all clinical problems pose the same difficulties!

There is no doubt that many teachers and students will benefit from having this source of very detailed case descriptions to consider and discuss together. Analysing each history provides insight into ethical principles and demonstrates that in practice there are often complicating factors that have to be taken into consideration, including the uncertainties inherent in both medicine and ethics. The moral principles involved in each case often appear to be conflicting, and make clear the difficulties faced by the practising doctor.

Of great value are the authors' commentaries at the end of each chapter, which analyse the problems and show ways towards the resolution of the ethical dilemmas that are posed in various situations.

This book is a useful addition to the medical ethics literature both because of the well documented and interesting case histories, and for the commentaries which are lucid and informative. Though mainly of use for those either teaching or learning about health care ethics it will also appeal to medical practitioners, nurses and other health care workers interested in good clinical practice.

Changing Ideas in Health Care

Edited by David Seedhouse and Alan Cribb, 236 pages, Chichester, £9.95, John Wiley and Sons, 1989

This book contains a collection of articles which describe attempts to facilitate increased public participation in health care. These have taken place in a variety of social settings including a national heart-health education programme; city and community-based initiatives; and hospital and hospice
schemes aiming at more democratic and socially-based patient involvement. The editors claim that three main ideas link these initiatives. These are: 1) 'holism', which attempts to locate all questions about health and ill-health in the wider contexts of lifestyle, culture, and political debate (page 3); 2) 'equality', which also incorporates acknowledging and representing social differences; and 3) 'autonomy', which involves enabling people to have greater control over their lives in terms of health generally as well as medical regimens. All of this is entirely laudable and, to a certain extent, the initiatives described do represent some much needed steps to put a broader, structurally-based concept of health back on political and medical agendas. However, as the editors themselves acknowledge, many practical and moral dilemmas remain. Not the least of these is the fundamental question of power: who decides what is health? Arguably, some of the population-based projects, although aiming to listen to people's needs, still end up imposing their own biomedical definitions of health; and the patient-based schemes still have to operate within biomedically determined parameters. Is this 'change' or merely the superimposition of social awareness onto the existing system? Moreover, can such initiatives ever hope to facilitate real change whilst power structures remain wedded to individually-based concepts of health to the neglect of social factors? There is also a practical problem with traditional methods of evaluating the success of these new approaches. The more participatory and dynamic the initiative, the more process and outcome are inevitably intertwined. Who, for example, defines what is a successful or desired outcome once the parameters of health are moved away from biomedical determinants towards those concerned as much with life enhancement?

This book provides good examples of practical initiatives in medicine and in health which should encourage and inspire those working in the field. However, given prevailing power structures, it raises more questions than it answers about possibilities of real change. Ideas may not be enough!

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Personal Data Protection in Health and Social Services

P Pearce, P Parsloe, H Francis, A Macara and D Watson, 134 pages, London and Sydney, £19.95 hardback, £8.95 paperback, Croom Helm, 1988

Information is a key resource in the provision of health and social services. It is also a resource whose character and availability has been transformed by technology in the last two decades. The extensive introduction of computers has expanded the capacity for bureaucracies to collect, store, manipulate and retrieve information. And because information is closely connected to deeply held sensitivities about privacy, secrecy and integrity, there has been growing pressure to regulate the use of information. One of the most notable results has been the 1984 Data Protection Act. This piece of legislation is intended to establish control over the use of automated information and to allow people ('data subjects', in the jargon of the Act) to have access to that information.

The simple outlines of the Act, however, cover a multitude of issues. Clients of agencies and bureaucracies are not the only people with an interest in the information. Medical confidentiality, for example, is not something that can be observed in all cases (for example, notifiable diseases); equally access has to be constrained where information about one person refers to another. Personal Data Protection in Health and Social Services studies these issues in the context of the new legislation (although the book seems to have been written before the Act was fully implemented).

The authors, with backgrounds in law, social administration, medicine and the social services, are agreed that the use of technology does not in itself transform the arguments about the ethics of data collection and use. On the other hand, given the immense capacity and speed of computers, the question as to what information ought to be collected, in what form and for what purpose has to be answered with a new urgency.

Penelope Pearce sets the background with an elegantly lucid survey of the current state of English law on 'information' and the changes made by the Data Protection Act. Neither the new nor the old law gives a general right to information. The 1984 Act merely grants 'a right of subject access'. But even this modest intention, argues Pearce, is not easily implemented. The Act makes it difficult for data subjects to assert their legal rights. They have to know where to look, to know who is collecting what under which heading. And if the local authority is registered as a single user, rather than as a group of discrete agencies with separate registration, then it is able to transfer information from agency to agency without the citizen's consent.

At the same time, the Act can actually inhibit disclosure where it might be beneficial. This is the result of a desire to protect the source of information and the privacy of third parties. If these others can be identified in the record, then it cannot be disclosed. In theory this could prevent access to almost all medical records since the source is bound to be known to the patient. Another constraint on disclosure is the requirement that the data not be harmful to the subject. But there are obvious difficulties here: how is harm to be judged? and how can redress be sought without the 'harmful' data being known about? A final problem posed by the Act is the absence of guidance as to whether parents have the right to access information about their children.

All these topics reappear in the subsequent chapters, which analyse the practical application of data protection and access. Phyllida Parsloe devotes her discussion of the social services to establishing an appropriate code of conduct for data use. The social services tend to operate a de facto open access system, but for it to work properly there have to be principles to guide the collection and recording of information. Parsloe emphasises the need for a clear sense of the purpose for which information is collected. Equally, third party protection has to operate in information relating, say, to child abuse. If sources cannot be protected, they will not participate.

A striking difference emerges in the practices of social and medical services. Where the former favour openness, the latter work within assumptions of confidentiality. Parsloe argues that this is justified by the different client-professional relation involved in each case. The argument is not fully developed, but it deserves further exploration.

The particular case of medical information is addressed by Huw Francis and Alexander Macara. They argue that the doctor-patient relationship depends on trust, expressed in confidentiality, but that