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Book reviews

Gene mapping: using law and ethics as guides

Edited by George J Annas and Sherman Elias, New York, OUP, 1992, xxiv+292 pages, £35.00

The subtitle of this excellent collection of essays draws our attention to the fact that in the case of the Human Genome Project money has been allocated through the National Center for Human Genome Research in the United States specifically to a programme examining the ethical, legal and social issues (ELSI). Hence, unusually in scientific research, the ethicists and lawyers have an opportunity to 'guide' the research.

This volume takes the reader through all the main ethical aspects of the project to map the human genome: the question of the moral distinction between somatic and germline gene therapy (here regarded as difficult to uphold); privacy and control of genetic information, including the possible consequences of genetic testing for insurance and employment, and the danger of the reinforcement of racial prejudice.

The strength of the collection lies neither simply in that it has assembled many of the big names in the American bioethics community, nor in the range of ethical issues covered, but in the way the issues are set in historical context and related to underlying philosophical questions. For example, articles by Swazey, Proctor and King examine precedents and the lessons they can teach the policy-makers of the present. As King points out, the American experience of sickle-cell screening is hardly reassuring. She argues that those involved with gene mapping should make efforts to ensure that the beneficial results of the work are not denied to ethnic minorities. In one of the most interesting contributions, Proctor compares 'genomics' (a term that covers mapping and sequencing) and eugenics, and suggests that it is over-optimistic to believe that abuses are necessarily a thing of the past, when we survey contemporary developments in different parts of the world.

Proctor further argues that whereas many people are anxious about the social control that may result from the genome project, the *illusion of control* is what we should fear. The mapping enterprise may lead to the view that people's problems are thought to be essentially genetic. The theme of biological reductionism and determinism is taken up in a number of essays and is illuminatingly discussed by Shuster, who says, 'the emergence of life escapes the model intended to explain it'.

In addition to this philosophy of science strand, Caplan points to the necessity for conceptual clarification of the concepts of health, normalcy and disease. What we consider to be a disease, he says, will be important in shaping the way the results of the project are utilised.

The paper by Walters urges the formation of a national advisory committee on genetic testing and screening. He notes that although both gene therapy and genetic screening involve applications of recombinant DNA techniques, the two technologies have been treated quite differently, gene therapy receiving by far the greater share of attention from policy-makers. He cites Capron, however, as saying that screening is the more probable source of harm with its potential threats to individual interests in insurability, employment and reproductive freedom.

As regards the latter, although the prevailing view is that genetic counselling should be non-directive, there has been recent questioning of traditional ethical principles in the genetic context, and King points out that 'non-directive counseling may not be an achievable goal for future counseling programmes'. This is because non-directive counselling may depend on counsellor and counsellee sharing value assumptions.

Although this book arises out of the American scene the issues have relevance for those in Europe considering these questions. It is not possible to discuss all the contributions here but the volume will be of considerable value to all who are working in this area.

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Practical medical ethics

Alastair Campbell, Grant Gillett and Gareth Jones, Oxford, Oxford University Press, 1992, 177 pages, £15.00 pb

Three eminent members of the University of Otago have combined to produce a text in medical ethics that is primarily, though they hope not exclusively, for medical students. The material is generally clear and well presented and, in terms of its principal intended audience, covers a good range of problems. Naturally, the expected topics such as abortion, euthanasia, AIDS and mental health are there, but there are also chapters on the foundations of medical ethics, the status of the body and its parts, medical research, needs and justice, and the problems of etiquette, malpractice and compensation. The welcome discussions of treatment

across cultures and of genetic engineering appear (for no obvious reason) as appendices. There is no doubt that the book would be useful in providing students with an account of all these problems, and I will not take issue in a short review with any of the arguments used in their presentation. It is more appropriate, perhaps, to look briefly at the general approach and style of the book.

Having stated at the outset that medical ethics is part of applied moral philosophy the authors continue with some brief remarks on the historical background. Socrates, Plato, Aristotle, Hume and Kant fly by in less than four pages, including Kant's view of ethics in eight lines. Is it worth doing at such speed? I suspect that students can do little with this survey other than quote from it, encouraging the view that a fleeting reference from secondary sources to the great thinkers of the past is an essential part of applied moral philosophy. The subsequent discussion of utilitarianism and virtue ethics seems more pertinent, though 'the greatest good for the greatest number' (page 4) is unfortunately, like its better known variant, a misleading way of introducing the former. From here we are taken, via the Hippocratic oath, to certain principles that we should keep in mind, those concerning non-maleficence and beneficence, autonomy, professional integrity and justice. I can see no theoretical objection to the use of principles of this kind, though the reference to the role of the underlying value of care in cases of their conflict (page 12) is rather unclear. The practical problem is that the introduction of these terms at an early stage can have a stultifying effect on a student discussion that is happily proceeding in terms of harm, benefit, choice and fairness. I am not sure that the term *'techne'* will help much either, especially when appearing from nowhere (page 15) with only the obscure expression 'skilled form of knowledge' by way of cursory explanation.

The above criticisms concern just the first chapter on the foundations of medical ethics. Not everyone will share them, and even those who do will find that the rest of the material is entirely worthwhile despite them. Here the relevant criticisms are those of style and are fairly minor. Sometimes the writing strays into a familiar academic wordiness ('healing process' for 'healing', 'family unit' for 'family', 'abortion procedures' for 'abortions') and occasionally into that of the more respectable leading article ('steps must be taken', 'sound and experienced opinion', 'widely recognized and respected') but although it doesn't sparkle, it is always thoroughly readable.

I noticed only two mistakes in this well produced book. There is a possibly confusing ambiguity in 'reduced opportunity costs' (page 77), since in the technical sense the opportunity costs increase. And in the discussion (page 135) of sexual misconduct in psychotherapy, an impeccably Freudian typo transforms 'therapist' into 'the rapist'.

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Ethical issues of molecular genetics in psychiatry

Edited by R J Scram, V Bulyzhenkov, L Prillipke and Y Christen, Berlin, Springer-Verlag, 1991, 177 pages, DM 108

This volume contains papers presented and revised subsequent to discussion at a meeting to discuss the ethical issues arising from the application of molecular genetic technology to psychiatry, which was held in 1990 under the joint auspices of the World Health Organization and the IPSEN Foundation. The authors of the papers are drawn from a wide variety of disciplines, including psychiatry, genetics, religion and law. In the discussions of research techniques and the application of research findings to clinical issues, there is a presumption that the reader will be fully conversant with the relevant technical jargon and no attempt is made at translation for the lay reader or the genetically unsophisticated clinician. Although some of the papers such as that by Crow from London on the possibility of 'A single-gene locus for psychosis and intelligence' contain little ethical discussion, they provide the material for an understanding of other discussions of the complex ethical issues emerging in this rapidly advancing area.

Some themes recur. There is repeated reference to the success first in identifying the genetic pattern of the Medelian dominant inheritance of Huntington's Chorea and then in developing a test for the identification of carrier status. It is pointed out repeatedly that problems immediately flow from the fact that the test is not one giving total accuracy and that the handling of knowledge about carrier status imposes difficult ethical choices for a physician in possession of such information. However, such uncertainty of diagnosis and such difficulty over the handling of information in this relatively straightforward situation pales into insignificance beside the potential problems in terms of, for example, the appropriateness of termination of pregnancy or the control of the social exchange of information in respect of conditions such as schizophrenia, where a genetic cause is never likely to be more than an incomplete and partial explanation of the emergence of the condition and where it is unlikely that any certain predictions will be possible about the welfare of any individual carrying the relevant genes.

However, the problems attaching to the identification of the putative genetic substrate of the more common serious mental illnesses again fade into the background when consideration is given to the possibilities for genetic control of the more minor variations of temperament, intelligence and behaviour. In a very penetrating paper on 'The use of prenatal diagnosis for psychiatric diseases' Mattei from Marseilles sounds powerful notes of caution in respect of colluding with the parental search for the 'ideal child'. She mentions her experience in studying fetal material for evidence of Down's syndrome and discovering not uncommonly the presence of an extra Y chromosome. Despite reassuring the parents about the frequency of the latter abnormality and the lack of any close association with socially deviant behaviour, it is her experience that most parents seek out information from less well informed sources and nearly always seek a termination of pregnancy. Discussions of such issues are linked to the lack of clear dividing lines in psychiatry between normal and abnormal and the inherent dangers of becoming involved in the practice of eugenics.

In discussion of therapeutic possibilities of the new genetic technologies the potential dangers of introducing genetic material whose total possible range of action is unknown are highlighted. However, of ethically