Health care need

Per-Erik Liss, 141 pages, Aldershot, Hants, 1993, Avebury, £29.90

The debate about rationing health care is often conducted in a way that assumes we are able to measure the health care needs of groups and individuals. As this book makes clear, we are only just starting to develop a framework within which to measure health needs, predict the outcomes of treatments and define the conflicting priorities that influence resource allocation. This book is the attempt of a philosopher to organise our thinking about these complex issues.

Health care need is a revised version of a doctoral thesis published by Linköping University. It sets out to explore one frequently suggested criterion for allocating resources for health care. In many countries the link between resources and need is not explicit, but in Sweden the Public Health Act lays down that the policies of the health care system should be determined only by the needs of patients. The book draws on a wide range of work across Europe, the United Kingdom and North America.

The book follows a logical progression. It looks at the use of health care indicators and points out that indicators of less than perfect health do not establish a need. Neither does the established use of services indicate a need. Three possible definitions of health need are discussed: the supply notion, in which a health need depends on the existence of a suitable treatment; the normative notion, which states that the existence of a health care need is a matter of opinion; and the instrumental notion, which defines health need in terms of the availability of equipment and facilities within the health care system.

These definitions are closely argued and lead on to further chapters discussing the concept of need, concepts of ill health, and ranking health care needs.

The closing section of the book suggests a model for assessing health care. Need assessment should involve establishing the actual health state of individuals, setting the goals of health care, and determining whether there is a treatment that will bring about a transition between the actual state and the goal. Health needs, defined in this way, are linked to helping people reach their own goals – the things that will make them happy.

Health care goals may be chosen, and it is the making of these choices that brings health care needs into existence. Defining these goals within society requires the involvement of professionals and citizens within representative bodies, whether these are democratically elected or health authorities.

The book does not reach the practical level of tackling the problems faced by health service researchers, clinicians or managers in defining needs, allocating resources or making choices between individuals. These are areas that remain complicated and difficult to work in. Many people are already working in the discrete areas discussed, although some applied research could benefit from the clarity of thought in developing an ordered approach to the subject. Initiatives such as the NHS Research and Development Strategy have supported the concept of identifying effective treatments, but are less clear about criteria for allocating resources to support these treatments.

The book does not give a list of easy answers. Clinicians and managers alike will struggle with it. However, it will provide a challenge to those who read it.

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Brain dead, brain absent, brain donors: human subjects or human objects?

Peter McCullagh, 261 pages, Chichester, 1993, John Wiley & Sons, £34.95

Replacement therapy is now well established as the preferred treatment for several hitherto fatal conditions and severe chronic diseases. However, if transplantation is available to only a minority of likely beneficiaries. In countries where effective programmes do not exist, the shortfall in the supply of organs and tissues suitable for successful replacement is a serious limitation. This book addresses the ethical issues pertaining to the use of those about to die or who are doomed to a futile existence as sources for much needed species-specific organs or tissues in optimal physiological condition. Utilisation of these resources requires medical interventions of a non-therapeutic nature which threaten to degrade the human individual from subject to object.

As stated by the title, the author’s chief concern is with the application in this context of present-day concepts of brain death and of so-called brain absence. The historical approach is well suited to this purpose and he succeeds in presenting information and opinion with clarity and objectivity. I recommend the book to policy-makers concerned with the harvesting of human transplants material, to the workers that do it and to potential donors or recipients.

McCullagh has avoided undue use of medical, legal and philosophical jargon and succeeds in leading the reader through some deep and turbulent waters. He is rightly critical of the misleading and often inaccurate information issuing from so-called experts, which is published in the news media and he gives some good examples of the obfuscations and gyrations performed by self-interested persons and groups. He accepts that the value of certain replacement therapy is sufficient to force re-appraisal of previously held attitudes and practices about death and the sanctity of human organs, but he has no patience with exponents of innovative treatments, whom claim to human (fetal or neonatal) ‘cadaveric’ material is based on frail but widely publicized evidence of efficacy.

Without the contribution from ‘brainless’ individuals there would be little progress in replacement therapy and many patients would have to endure potentially treatable suffering. Peter McCullagh has set out in impressive fashion and in appropriately detail the ethical implications of the rush to procure tissues and organs from donors who have beating hearts but who are not ‘brain living’. 
At £34.95 this is not an easily affordable book but it deserves to be widely read and used as a basis for information and discussion.

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Perilous knowledge

Tom Wilkie, 195 pages, London, 1993, Faber and Faber, £22.95, £14.99

Perilous Knowledge is perfectly timed. Tom Wilkie’s balanced discussion of the social and ethical implications of the human genome project will be welcomed by all those who are concerned by reports of gene therapy and ‘gay genes’.

The book is divided into two sections. The first covers the history of molecular biology and describes how scientists have progressed from Darwin’s complete ignorance of genetic material to our present-day sophistication. The second section considers the implications of the human genome project, taking a historical point of view. Wilkie wisely avoids wild speculation about future revolutions and instead examines how our limited genetic knowledge has been used and abused in the past.

Chapters 2–4 provide an introduction to molecular biology and its history. Despite its rather hyperbolic style, the text reads well and carries the flavour of the subject. Unfortunately, Wilkie’s vow to avoid jargon and his seeming dislike for diagrammatic illustration will leave the uninitiated only superficially informed. We learn about the discovery of the structure and function of DNA. The concepts of genes and protein synthesis are presented with a description of some of the most closely studied single gene diseases.

The human genome is compared to a public library, each of the 46 bays representing a chromosome. The challenge of gene mapping and genome sequencing is to locate and read all the 50,000+ meaningful volumes (the genes) in the midst of the apparent gibberish which constitutes more than 90 per cent of the library.

Some of the technical advances which underpin the genome project and the associated biotechnology industry are mentioned in a chapter that attempts to explain recombinant DNA technology, bacterial and viral genetics, gene splicing and more. The history of molecular biology is then rounded off with a fascinating analysis of the origins and emphases of the European and American genome projects.

The second half of the book is a ramble through the potential ethical confusion which threatens to engulf a scientifically naive society. The thrust of much of the commentary is that the new knowledge will be abused, not out of malice and hysteria, but out of ignorance and hysteria.

Wilkie worries that only the rich will benefit from the new knowledge and that the poor will become a genetic underclass. Darwin told us that Man is born unequal, allowing natural selection to mould us. Galton’s nineteenth century eugenics sought to replace natural selection with a programme of selective breeding. Wilkie presents a modern world where genetic screening and selective termination will permit the creation of designer children.

When the future of reproduction is so cool and logical the temptation is to think of our humanity as nothing more than a biological computer programme. James Rachels is quoted as decrying conventional morality as ‘speciesist’ because H sapiens and other animals are no longer in different moral categories. Here, surely, is the ultimate in the humbling of Man, our moral worth is nothing more than the richness and complexity of our programme.

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Pro-life? The Irish question

Michael Solomons, 86 pages, Dublin, Ireland, 1992, Lilliput Press, £3.95 (Irish puns)

The title of this book is a superb choice. The question Pro-life? is deeply provocative and philosophical in its implications. Michael Solomons scrutinises what ‘pro-life’ means in the Republic of Ireland and does this from a position of one who has lived in Ireland all of his life. Born in Dublin in 1919, Solomons was an obstetrician-gynaecologist until his retirement in 1988. The book was written against the background of acrimonious Irish debate about abortion which has gone on virtually uninterrupted since 1981. This debate was intensified in 1992 when a 14-year-old rape victim was served a High Court injunction, initiated by the Attorney General, preventing her from legally travelling to England for an abortion. A society which goes to such lengths to prevent a rape victim from having an abortion might be explained by its history and Solomons’s study provides a great deal of that history. In Pro-life? The Irish Question, Solomons tells the complex story of Irish policies on contraception and abortion over the last seventy years. Ireland’s laws governing matters of reproduction have resulted from the interaction of religious, cultural, legal and medical institutions which have traditionally reinforced a pro-natalist viewpoint, reiterating women’s ‘proper moral roles’ as mother and reproducer. The national hegemony of the Roman Catholic Church in the republic has provided the main institutional support for religious orthodoxy on questions of reproduction.

Abortion in Ireland has been legally prohibited under the British Offences Against the Person Act of 1861. In rare cases such as ectopic pregnancy, therapeutic abortions have been quietly tolerated in Ireland under the traditional principle of double effect. In September 1983, after two years of acrimonious public debate on abortion, a national referendum passed the Eighth Amendment to the Irish Constitution which reads: ‘The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to protect, and as far as practicable, by its laws, to defend and vindicate that right.’

The ambiguities of meaning in this amendment were noted from its first publication. In debating the amendment, many voices had argued that a constitution is not a suitable mechanism for determining abortion policies within a country. Events in Ireland since 1983 have confirmed that judgement. The Irish legal ban on abortion in no way reflects the reality of abortion choice by Irish women. Since abortion became legal in Britain in 1969, it is estimated that 5,000 women each year travel to Britain for abortions. However, this figure is almost certainly an underestimate. For many Irish women who choose abortions in England do not use an Irish address for fear of identification authors'