

Book reviews

Ethics, Reproduction and Genetic Control

Edited by Ruth Chadwick, 200 pages, London, £8.99, Routledge, 1987

The first child born as a result of *in vitro* fertilisation (IVF) is now over ten years old. After a decade of technical marvels in reproduction including embryo transfer and freezing, and pre-implantation genetic diagnosis, follows the uncertain business of creating moral terms of reference to deal with their application. Ruth Chadwick's collection of essays attempts to do just this and she has gathered some of the world leaders in their prospective fields of science, medicine and law to address ethical issues. It is revealing that the Director of Research of France's CNRS, Jerome Lejeune, emphasises fetal-centred debate and minimises women's role in reproduction to that of carriers by comparing embryos to self-determining astronauts and the role of a mother to that of 'a life capsule' and 'the mother ship'.

Chadwick establishes reproduction as more than a private act that should be accountable to public policy. The failure of policy formation in Britain is put forward by the ethicist, R M Hare who criticises the Warnock Report for its lack of an ethical standpoint which has left the reproductive technology debate open to intuition and prejudice (as with the issue of whether to continue with embryo research or not). He offers a utilitarian approach which would enable state control and public accountability for the way in which reproductive techniques and related applications such as surrogacy are regulated. In a religious context the Board for Social Responsibility of the Church of England argues for the same thing. The board's article embeds issues of reproductivity within the Christian ideal of a proper procreative place

(marriage) and from the Protestant perspective, views most of the technologies (including embryo research) as ways of sustaining 'the goods' of Christian marriage. Both sides agree that the technologies should be limited to the nuclear family for the sake of the child although it has not been proven that this is the best place for raising children.

The dichotomy between religious morals and the value of technological development is revealed in most of the arguments in this collection in that restrictions on the use of these techniques are qualified chiefly by a hesitation in embryo manipulation. In both sides of the argument mothers rate hardly any mention and the idea that an ethic could be developed from their particular experience is raised only briefly by Chadwick in a reference to Mary O'Brien's theory of 'reproductive consciousness' and is not related to the discussion as a whole. The result of this dichotomy, which I see as false, is a fetal-centred debate and an ethic which effectively denies women's procreativity both physically and as a thoughtful undertaking.

In the second half of the text Chadwick examines genetic engineering, both pre-implantation and post-conception. She concludes as does W French Anderson, one of America's leading geneticists, that the engineering of human cells, both somatic and germline (which affects subsequent generations' genetic make-up) are morally justified if used to prevent or cure disease but not to enhance human qualities. However, another well-established genetic scientist, Robert Sinsheimer, reveals there is more to genetic engineering than the control of disease: 'We can be the agent of transition to a whole new pitch of evolution. This is a cosmic event'. The discussion of new eugenics practised in Singapore by C K Chan is a sobering example of the possible realisation of

such dreams. In Singapore the state actively promotes reproduction among the educated and prevents it in the poor and un-educated in the hope of creating a super-intelligent gene pool.

Sex-selection is another form of eugenics which reproductive technology facilitates. Dharma Kumar properly defines the practice of routine amniocentesis followed by abortion of female fetuses in India as a social rather than technological problem. My concern with his conclusions, as with most of the ethics discussed in this collection, is that the crucial roles of feminism as activism and theory have played (it was feminists who drew public attention to female infanticide in India) is ignored or misrepresented. Meanwhile, various morals are assigned to the embryo and an ethic which promotes technological solutions to social problems is sustained.

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Human IVF, Embryo Research, Fetal Tissue for Research and Treatment, and Abortion: International Information

Jennifer Gunning, 44 pages, London, £7.50, HMSO, 1990

This summary of the current position as regards the law and practice of *in vitro* fertilisation (IVF), fetal research and abortion in countries providing IVF allows comparison of the situation

between countries. I assume, although this is not actually stated, that it is intended as a comprehensive survey.

The first thing that strikes me, as a worker in the IVF field in the United Kingdom, is that we alone in Europe have no system for financial reimbursement of our clients. Not only is there no provision through the National Health Service, but the private health schemes in the United Kingdom contain exemption clauses for this treatment. I feel that IVF is now standard treatment and arguably the most effective medical intervention in infertility and should be recognised as such under the National Health Service. It is interesting that the research project was funded by the Department of Health and I hope it is considering righting this anomaly.

There is however no explanation of the reason for the support of the DHSS and this proves eventually to be a frustrating aspect of the book. Nowhere does the author say why the project was undertaken, nor does she discuss her findings. There is a chapter on the need for uniformity under the Council of Europe and Ms Gunning explains the usual process for obtaining consensus and the role of the *ad hoc* Committee for Bioethics. Perhaps the data was collected to inform this committee and it certainly shows the great disparity between the member states of the European Community. But this does not explain why the data from Australia, Canada and USA is included. If the data is intended to be complete then the data from Austria should be included. It is also frustrating that having discussed in some depth the legal situation in all the other countries the author does not give the same attention to the United Kingdom data, merely including it in the tables.

[Though it should be added that the position of the law here is difficult to determine until implementation of the Human Embryology and Fertilisation Bill].

The book will however be useful to people working in the IVF field just for the raw data it contains. I personally shall also find it an intriguing pastime analysing the consistency in policy for each country between embryo research and abortion and making associations between, for instance, the population policies and religions of those countries.

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Assessing Quality of Life

Edited by Stefan Björk and Johannes Vang, 104 pages, Linköping, Sweden, \$25, Linköping Collaborating Centre, 1989

This volume is the first in a planned series of Health Service Studies from a WHO collaborating centre at Linköping University. In eight chapters it presents the proceedings of a conference of quality of life (QOL) hosted by the Centre for Medical Technology Assessment at Linköping University. The first three chapters are conceptual and philosophical, attempting some semantic 'ground clearing' on the origins of, and relationships between, concepts of QOL, happiness and social welfare. The remaining chapters focus on the practical issues of how and why QOL should be measured in health care evaluation studies, particularly in clinical trials, and the way in which a composite indicator of health outcome – the ubiquitous Quality-adjusted Life Years (QALYs) – could be used to prioritise the allocation of scarce health care resources.

Given the focus on health care, the book might benefit from an early distinction between QOL as a general concept and so-called health-related QOL. Initiatives to quantify the latter find origin in measures of functional (physical, emotional, social, etc) status and activities of daily living, whereas more global concepts of QOL would embrace a wide variety of influences on life satisfaction that may have little or no relationship with a person's health status. (The fact that I cannot afford a new BMW may have a modest negative effect on my global QOL but is not having any discernible impact upon my health status.)

Readers not familiar with the QOL literature are spirited rapidly and somewhat uncritically through the various QOL instruments such as the Sickness Impact Profile (SIP) and the Nottingham Health Profile (NHP). There are important differences between these two instruments that potential users should be made aware of – while it is possible to compute an overall SIP score (over all domains), this is not possible with NHP. Thus in a trial of treatment A versus B, each of the six NHP domains (for example pain, physical mobility, etc) would be computed separately for each treatment and any definitive statement of overall

health-related QOL superiority would require one treatment to be superior in all six domains.

A major omission from this volume is any discussion of utility measurement techniques such as standard-gamble and time-trade-off which are being used increasingly to construct composite health indices combining survival and QOL according to patient preferences. The uninformed reader might be forgiven for thinking that QALYs can easily be calculated from some combination of SIP or NHP and survival data, but this is not the case. The construction of QALYs requires somebody, somewhere, to make an implicit or explicit trade-off between combinations of quantity and quality of survival.

The use of QALYs by health economists raises a number of philosophical questions which are only briefly addressed in this volume. The ethical foundation of economics is a concept of social welfare based upon utilitarianism – the greatest good of the greatest number. But this efficiency criterion is silent on issues of equity or distributive justice. Prioritising health care interventions in terms of their cost per QALY assumes that society places the same value on one QALY gained irrespective of whom receives this benefit. In some situations society may prefer to forego some efficiency to gain distributive or fairness objectives. Such efficiency-equity trade-offs are a challenging area for future research.

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The Social Consequences of Genetic Testing

Edited by H Rigtter, J F C Bletz, A Krijnen, B Wijnberg and H D Banta, 106 pages, The Hague, Holland, available free on application to Scientific Council for Government Policy, PO Box 20004, The Hague, The Netherlands, the Netherlands Scientific Council for Government Policy, 1990

This useful text is the edited version of the proceedings of a conference held in Leidschendam on 16–17 June 1988. Genetics and genetic testing and the