9:2 Summer 1993

ETHICS & MEDICINE

An International Christian Perspective on Bioethics

Editorial Policy

Ethics and Medicine seeks to develop a Christian mind on the complex and fundamental challenges posed to society by technological advance in medical science.

Instructions to Contributors

Contributors are given liberty of expression in their development of ethical thinking within a Christian perspective.

Articles for publication are welcomed by the Editor. Publication is subject to academic refereeing as well as general editorial judgement. Material may be returned for revision before publication.

Contributors will be notified as soon as possible of editorial decisions, though this process can take some time.

Contributors are asked to follow the pattern of published material for length, subheadings and so forth. Different referencing conventions acceptable provided consistency is maintained within the paper. An outline c.v. should accompany each paper.

Editorial Addresses

In the UK: Centre for Bioethics and Public Policy,
58 Hanover Gardens, London, SE11 5TN
In the USA: Trinity Evangelical Divinity School,
2065 Half Day Road, Deerfield, Illinois 60015

Copyright

Indexing

Articles are indexed in Religion Index One: Periodicals (RIO); book reviews in Index to Book Reviews in Religion (IBBR); published by the American Theological Library Association, 820 Church Street, 3rd Floor, Evanston, Illinois 60201. The indexes are also available online through BRS Information Technologies and DIALOG Information Services.

Subscription Rates

Ethics and Medicine is published by Paternoster Periodicals three times yearly. Subscription rates are as follows:

1 year
UK £9.75 USA $31.05 Overseas £10.35
2 years
UK £19.50 USA $62.10 Overseas £20.70

Cheques (made payable to 'Paternoster Periodicals') should be sent to Paternoster Periodicals, P.O. Box 300, Carlisle, Cumbria. UK. CA3 0QS.

Advertising

Ethics and Medicine is pleased to accept advertising: current rates available from the Publisher. Readers are asked to note that advertising does not imply editorial endorsement.

Typeset by Photoprint, Torquay, Devon.
Printed in Great Britain for Paternoster Periodicals,
P.O. Box 300, Carlisle, Cumbria. UK. CA3 0QS by
BPCC Journals Ltd, Exeter.

ISSN: 0226–688X

From the Editor

A DECADE FOR DEATH

The 1990s look set to go down in history as the decade in which our culture decided to turn its back on one of its most ancient and entrenched taboos, the refusal to kill our own kind. It is a considerable irony that this sea-change comes hard on the heels of another: the retreat from killing our own kind in those circumstances traditionally seen as exceptional—in the capital sentence, and in war.

Of course, if we choose to bring abortion into the argument, it goes back a generation. And there is no doubt that the cavalier taking of human life *in utero* has well-staged the set for *ex utero* euthanasia. But such an awareness must not be permitted to dull our perception that we are standing on the northern shore of the Rubicon; and the common character of these debates in many nations reveals the alarming extent to which the culture has already been corrupted.

In the Netherlands, of course, a decade of euthanasia practice seems finally to be gaining statute support. In the United Kingdom, a House of Lords committee is assessing options in the light of several draft bills. In the United States, the 'living will', promoted from euthanasia tactic to public policy, is becoming *de rigueur* as fear of health-care costs and fear of the dying process together exact a major tribute from consensus medical ethics. We may well doubt whether 'aid-in-dying' referenda can long be held at bay, and whether the curate's egg of national healthcare debate can avoid resulting in a severe regime of rationing. Certainly, there are too many factors pulling together in this wealthy and fractured society for us to have any confidence that things will get better before they get much worse.

We are standing on the northern shore of the Rubicon and the common character of these debates in many nations reveals the alarming extent to which the culture has already been corrupted.

And if thus in the west, in the world's long- and still-dominant culture which has flown the flag of the sanctity of life and continues to harbour most of our worldly wealth, what of the rest? What of the 'third world', especially those whose struggling medical systems are beset with an AIDS problem much greater in proportion than any in the west? What of the newly-developed nations of east Asia?—whose social infra-structure lags far behind their GDP and for whom old western influence in the shape of the Gospel and new western influence in the shape of secular humanism vie for effect. And what of the liberated societies of central and eastern Europe? The Russians are reported to be seeking the reintroduction of the Hippocratic Oath. Perhaps it has taken the comprehensive laying waste of their value-system for this great nation to see that distinctive and shared values are at the heart of the medical enterprise just as everyone in the west runs lemming-like in the opposite direction.

The Russians are reported to be seeking the reintroduction of the Hippocratic Oath. Perhaps it has taken the comprehensive laying waste of their value-system for this great nation to see that distinctive and shared values are at the heart of the medical enterprise just as everyone in the West runs lemming-like in the opposite direction.

The point, however, is this. These coincident debates in western countries will set the tone for generations of medical practice and public policy all around the world. The exigencies of healthcare funding in Western Europe and the US, the cleverness of the tiny lobby for euthanasia who have so played on the fears of the public, the folly of overtreatment and failing confidence in physicians, our failure to engage the hospice alternative—all these things are shaping a debate whose fateful consequences will soon spill over into a new world order in medicine. The challenge of the hour is very great.

B. S. Cusveller and H. Jochemsen, respectively Research Associate and Director of the Prof. dr. G. A. Lindeboom Instituut, Ede, The Netherlands.

THE NEW DUTCH 'MEDICAL EXPERIMENTATION BILL' AND INCOMPETENT PATIENTS

INTRODUCTION

Recently (spring 1992), the Dutch Government sent a bill to the 'Second Chamber', called 'Regelen inzake medische experimenten' (the 'Medical Experimentation Bill', hereafter MEB), covering scientific research with human subjects in medical situations. Both in Parliament and in society there is a large consensus about the aptness of this Bill. It is in agreement with the Declaration of Helsinki and of course with the Dutch Constitution (Explanatory Memorandum, p. 5). In some of the clauses in the Bill regulations are made for experiments on those not competent to give their informed consent to these procedures. Since we are committed to the view that the lives and dignity of those incompetent persons deserve our utmost respect and the best legal protection, we have critically examined this Bill.

In recent years, the awareness of the moral status of human research subjects as well as the importance attributed to patients' rights has grown considerably. This is demonstrated by the increased attention that is being paid to research subjects' consent to participation, to the weighing of their risks and benefits and to their privacy and so on. As a result, many review committees have been established, judging research procedures on their acceptability in terms of moral, legal and scientific considerations. Although there were some preliminary regulations, neither the experiments nor the reviewing committees had a solid legal basis. Not that much abuse or violation of informed consent was found, but morally, legally and scientifically good research wasn't guaranteed either. There was some variation in the applied norms—although generally the Declaration of Helsinki was followed—in the application of norms, in the establishing of review committees, in the disciplines represented in those committees and in the degree to which researchers were committed to having their experiments reviewed. In short, ethical review of medical experiments was mostly a voluntary, non-obligatory affair, both regarding the requests for reviews and regarding the judgement of the committees. So standardisation of review procedures and a legal basis was called for.

THE BILL

The new Medical Experiments Bill contains the following (in no particular order):

- The Minister of Public Health appoints a 'National Review Committee' (Art. 12.4), which has the responsibility for the recognition (Art. 14.1)—and the withdrawal thereof under certain circumstances (Art. 20)—of local review committees, reviewing first of all the statutes of those committees (14.2.b–d).
- The National Committee consists of experts in medicine, nursing, pharmacology, law, ethics, behavioural sciences and in the methodology of scientific research (Art. 12.2).
- The National Committee is the only body to give permission for research on genetic intervention in human body cells (Art. 2.2.b.3) and on children and incompetent persons (!) (Art. 2.2.b.2).
- Each institution wanting to conduct research is obliged to install a recognised review committee, consisting at least of a doctor, a lawyer, a researcher and an ethicist (Art. 14.2.a).
- Each researcher is obliged to draw up a research program ('protocol') and have it reviewed (Art. 2.1, 4.5). She or he is confined to the final judgement of the review committee (Art. 2.2.a). In case of rejection, the researcher may appeal to the National Committee (Art. 18.1).
- Each submitted research protocol and every judgement of local committees are centrally registered by the National Committee (Art. 17).
- Also the 'Inspectors of Public Health' have responsibility for the supervision of the observance of these regulations (Art. 23).
- This Medical Experiments Bill does not apply to experiments on human embryos and gametes, for which a separate Act is being prepared.

CONDITIONS

Before coming to the point of mentally incapable individuals, first the general norms for acceptable medical

research put forward in the MEB must be mentioned (in no particular order):

– It must be reasonably plausible that the experiments will yield new insights in the field of medicine (Art. 3.1.a).
– It must be reasonably plausible that these insights cannot be obtained by any other method, or by an experiment less intrusive on the subject (Art. 3.1.b).
– The experiment must satisfy the demands of correct scientific method (including that it must be theoretically and logistically satisfactory) (Art. 3.1.d).
– The experiment on human subjects must be preceded by adequate experiments in laboratory situations, on animals, human tissue, etc. (Explanatory memorandum, p. 10).
– It must be reasonably plausible that the benefits of the experiment for the subject outweigh or stand in acceptable proportion to the risks for the subject (Art. 3.1.c).
– For each experimental procedure there must be a research protocol which is to be followed (Art. 2.1, 4.5). No research may be done outside this protocol (Explanatory Memorandum, p. 8), every change in plans must be laid down in a change of protocol (for which the review committee and the subject again have to be asked permission) (Art. 8, 9, Explanatory Memorandum, p. 9).
– The performing researchers must display expertise both in scientific research and medical treatment necessary for this research (Art. 3.1.e).
– The experiment must be morally and legally acceptable (Art. 3.1.g).
– The research subjects must be informed (Art. 4.3) and asked for their written permission to their participation in the experiment (Art. 4.1). He or she must be given time for deliberation (Art. 4.4). Withdrawal from the experiment must be possible at all times. The subject cannot be held responsible for any consequences of his withdrawal from the experiment (Art. 4.6).
– The researchers must see to adequate insurances of possible risks (Art. 6.1).
– The privacy of the subject is to be respected as much as possible (Art. 10, 25).
– In cases where experiments may be life-saving and the subject is not able to give consent, *i.e.* in cases of emergency, the informed consent paragraph (and in some cases the permission of the committee) does not apply. Yet the other conditions, like the risk-benefit ratio and moral acceptability, still do! (Art. 4.2)
– In case of minors above the age of 12, written permission must be obtained from *both* the minors and their parents or guardians (Art. 4.1.b).
– In cases of people incapable of giving informed consent written permission must be given by their legal representatives (Art. 4.1.c).

RESTRICTIONS

People who are never to be subjected to medical experiments according to the Bill include:

– Persons under treatment by the same person doing the experiment (Art. 3.1.f.1).
– Persons in any business or professional relation to the researcher (Art. 3.1.f.4).
– Imprisoned individuals (Art. 3.1.f.3).
– Institutionalised (hospitalised) people may not be subjected to experiments that are not relevant to the condition giving rise to their institutionalisation (Art. 3.1.f.2).
– Minors, because legally they cannot give their permission (Art. 3.1.f.5, 4.1.d).

To the latter two categories there are exceptions. With respect to incompetent persons the Bill states the following. The basic rules are:

(a) When subjects have not given their written consent, experiments may not be performed on them (Art. 4.1.a–d).
(b) Institutionalized people may not be subjected to research not relevant to their condition (Art. 3.1.f.2).

INCOMPETENT PERSONS

So, the general rule for the legislation concerning medical experiments on incompetent subjects is: since they cannot give consent and since they are often institutionalized, they may not be subjected to experiments. Now, to this rule there are exceptions. Here we must divide between two sorts of considerations, *i.e.* considerations of individual interest and of general interest. Sometimes an experiment may be beneficial to the very research subjects themselves (Art. 3.2, 3.4.a). The National Committee may then allow the experiment on the ground of individual interest, provided the risk and discomfort of the experiment for the subjects are minimal and provided all other conditions are satisfied (Art. 3.3, 3.4.b). In other cases, a medical experiment may be highly relevant—*i.e.* directly beneficial—to the very category to which the incompetent subject belongs. The National Review Committee may then allow this experiment on the ground of general interest, again provided other requirements are respected.

In short, the Dutch answer to the question of medical research with incompetent individuals is this: no experiments on these individuals are allowed unless this patient himself or the category the individual belongs to cannot in any other way gain the direct benefit these experiments promise to offer, and the risks and the burden for the research subjects are minimal. One qualification must be added. Individuals incapable of giving their assent to participation in experiments may be represented by their legal representatives, *e.g.* their parents or spouse. Consent given by these representatives however, must satisfy the above mentioned demands, like written permission, judgement by committee, etc. For minors, representatives may be either their parents or guardians (Art. 4.1.b, 4.1.d); for other incompetent persons, representatives may include legally representative persons, such as parents, guardians, spouses or partners (Art. 4.1.c). This means these representatives form a smaller group than the 'Medical Treatment Act' allows (Explanatory Memorandum, p. 13). Not just

anybody can give permission on behalf of an incompetent person.

CRITICAL COMMENTS

The above is a short outline of the legislation proposed by the Dutch Government. As said before, a rather large consensus can be found for it. And in our opinion this is justified with respect to the main line of the Bill. Yet, this doesn't mean that no criticisms can be made.

a) On responsibility and legal liability, the Bill states that not only the very researcher is responsible for the performance of the experiments (Art. 5.1), but also the person or legal body that commissioned the experiments (*e.g.* the university) (Art. 5.2), the institution in which the experiments take place (*e.g.* a hospital) (Art. 5.3), and any third party that may assist or contribute to the experiments (such as pharmaceutical industries) (Art. 5.4). It is clear that where problems occur it will be enormously difficult to sort out who is responsible for what, if this Bill is not more specific in other regulations (some further qualifications are announced but are seemingly not sufficient). This Bill is also unclear on the division of responsibilities in the supervision of experimental procedures: what exactly characterises the tasks of the Inspector of Public Health (Art. 23) and of the National Committee (Art. 19.1), and how do they relate? Here too, additional regulations are required. It must never happen that the bodies involved are in doubt of their responsibilities or even escape them at the cost of others, notably at the cost of research subjects.

b) On the local committees the Bill states they have to consist of at least the four disciplines mentioned in paragraph (3) (Art. 14.2.a.). The National Committee consists of the seven disciplines mentioned in (3) (Art. 12.2). It should be noticed that among the participants in the committees there is no representative of the research subjects themselves, whether they be healthy volunteers or patients. Now admittedly, in the Explanatory Memorandum (p. 30) it is argued that research subjects do not form a well-defined group of people and this makes it impossible to have them represented in committees. In addition, the Memorandum argues that the members of the committees are appointed on the basis of their professional expertise alone. However, these arguments are not altogether convincing. In the first place, volunteers for non-therapeutic research may be hard to be represented. But in fact, many experiments are of a therapeutic nature and involve *ipso facto* patients. This category of research subjects may be represented by some patients' organisation. In the second place, patients or research subjects have a special kind of expertise, namely *experiential* expertise. This, it seems to us, is not unimportant. The researchers and the review committees are committed to the evaluation of the importance and the medical acceptability of the research and especially in the case of experiments with patients, to the weighing of the risk-benefit ratio of the experiments for the subject (Art. 3.1.b, 3.1.c). The adequate comparison and the weighing of such different concerns is very difficult. In this process the experiential expertise of a patients' representative will be of value.

Now, it may be argued that patients as research subjects necessarily have their say because they are asked their informed consent. However, hospitalised patients are in a situation of dependancy and may thereby feel pressed to give their consent (even though the researcher and the attending physician are different persons). Furthermore, the interests of patients in general, can surpass the interests of an individual patient, in the sense that what may be acceptable to an individual may not be desirable at a social level (*e.g.* experiments in the area of artificial reproduction). So, we conclude that it is desirable that a representative of research subjects/patients participates in the review committees, in order to specially look after the interests of research subjects, in particular when it concerns patients, or even incompetent patients.

c) Concerning the central committee, to the above the following may be added. Since this committee has great responsibilities and powers, their decisions may have great consequences for research policy in The Netherlands. Morally good decisions, however, are not just the outcome of professional expertise, but also of ethical, philosophical and religious beliefs. So, in appointing the members of the central committee, the Minister should always take into account the diverse ethical and religious views within health care. Also because of possible far-reaching consequences of decisions concerning certain experiments (*e.g.* with respect to embryo research), the Government may sometimes have to give additional legal regulations within which scientific research must take place (in fact a bill about embryo research is in preparation).

d) With these regulations alone, it is not always possible to guarantee morally good research. Surely, the Bill gives or refers to substantial norms (Art. 3, 4, Explanatory Memorandum). However, it is conceivable that unacceptable research goals might pass these regulations; the term 'reasonably plausible' of course is open to divergent interpretations. This is not to say such goals will actually pass the review committees. Hopefully and probably they will not. But the point is, that on the basis of the text of the law itself, people may not look for *good* research but for research that just fits the requirements. And this might give an opening to a slow and silent shift to less respect and protection for incompetent individuals.

Put in a different manner, the exceptions to the rule that no experiments may be performed with incompetent persons are formulated in quite general terms (Art. 3.4.a–b). It is not clear how strict or loose the formulation of the exceptions will be interpreted in practice. Much will depend on the decision of the local review committee and of the National Committee. Thus, the ethics of medical experiments with humans will in the long run become the ethics of health care professionals. In the light of other trends in medical ethics in our country this is not altogether reassuring to us. Therefore, we think that the formulation of the regulations of experiments with incompetent persons should be more strict.

The authors are indebted to Janice Price of the Centre for Bioethics and Public Policy, London, and D. J. Bakker, MD, for their criticisms and suggestions in response to an earlier draft of this manuscript.

Kenneth Prudhoe, General Practitioner, Gateshead; Council Member, Royal College of General Practitioners

THE NHS REFORMS—A VIEW FROM GENERAL PRACTICE

Most UK patients have never visited a general practitioner in this country and paid a fee for the consultation—the reason being that the majority of the population has grown up with the NHS and health care provision has been free at the time of need—and now two generations have grown up brain washed into regarding health care as free even though we spend billions of pounds each year on the NHS.

One of the stated aims of the NHS reform is to obtain better value for money and it sets out to achieve this by introducing a new framework of health economics in which Family Health Service Authorities and fund holding GPs are purchasers of health services. Hospitals are competing to provide health services, and patients are consumers—an internal market in health care. The same market place imagery is implicit in the new GP contract with its increased dependence on capitation income as a reflection of consumer satisfaction and with the introduction of targets and performance-related pay as a guide to professional success.

Better value for money is expected as a result of pushing resource management nearer to the actual providers of health care who should be in the best position to decide on community and individual health needs. It is an attempt to unravel the old conundrum of delegating responsibility down the health service hierarchy whilst, at the same time, encouraging accountability upwards (DHSS, 1972).

Low productivity and waste are to be further minimised by the mechanism of competitive efficiency.

These reforms are far reaching and produce a large number of ethical implications for GPs.

COST-EFFECTIVE OR CHEAP—DOES CHEAP MEAN WORSE?

By creating fundholding GPs and fundholding FHSA with resources to purchase hospital services, to pay staff and to cover prescribing costs, there exists for the first time in the NHS a mechanism for projecting costs in the demand-led primary health care sector.

The associated value for money or cost-effectiveness together with increased accountability are likely to be attractive arguments to anyone familiar with Biblical teaching on stewardship and the parable of the talents. However, a cost-conscious GP, anxious to keep within budget and thereby release funds for the practice needs, may confuse cost-effectiveness with cheapness. For example, it is cheaper to temporise with a truss than to refer for hernia repair or to put off with anti-arthritic tablets rather than refer for hip replacement—but is this cost-effectiveness and is it professional?

Society will rely more heavily than before on the professionalism of doctors who will need to maintain objectivity in their clinical judgement without succumbing to the economic pressures of resource management. It is this area which most exercises the minds of GPs particularly if future downward pressure on their funding exposes them both to patient dissatisfaction and also to patient suspicion about clinical objectivity.

STEWARD OR ADVOCATE?—MANAGER OR CLINICIAN?

The more immediate intrusion of resource management into the clinical judgement of GPs could conflict with the GP's role as patient advocate obtaining the best for each individual patient.

This commercialisation of the doctor-patient relationship will definitely affect the threshold for referral into the secondary health care sector and could eventually undermine the trusting dependence by the patient on the professionalism of the doctor. The implications for the weak or inarticulate or the naive would be a second-class provision of health care in clear contradiction to the Biblical warning against partiality in our attitudes (James 2:1–4). Whitehorse (1989) has highlighted a change in the ethic of medicine from that of beneficence bordering on paternalism to that of distributive justice in which the allocation of resources has become much more the doctor's responsibility. Fundholding practices will be particularly aware of a new tension of conflicting clinical and management responsibilities although the recent King's Fund Report (Glennerster *et al.*, 1992), based on the experience of ten fundholding practices, indicates that their purchasing power has improved the service provided in hospital contracts. However, additional ethical dilemmas have been thrown up as some fundholding practices have formed private companies from which they can buy services and consequently blunt the competitive edge of the purchaser/provider distinction. In a recent *BMJ* leader, Coulter (1992) questions whether fundholding will remain a small minority of well-organised larger practices with good facilities mostly in prosperous areas and thereby expose it to the charge that the scheme channels resources to those areas least in need—a charge which is

even more difficult to dismiss when the budget is also subsidised by the private health insurance of the better off. Clearly this *threat to equity* is an issue to address when establishing the formula by which budgets are decided and it represents an opportunity to undo the inverse care law which permeates most health care systems.

The prospect of an ever-increasing socio-economic health divide within each practice is a *threat to equity* which must be recognised and consciously resisted in the party political debate. The greater *threat to equity* is from fundholding GPs but many fund holders have sought actively to ensure that any contracts they agree do not prejudice or delay the service to NHS patients from nonfundholding practices (Glennester *et al.*, 1992).

PATIENT RESPONSIBILITY AND PATIENT CHOICE

Another subtle transfer of responsibility to general practice results from the obligation placed upon GPs to take responsibility for their patient's general health through doctor initiated health screening, vaccination and cervical smear programmes. This assumption of responsibility by doctors, when patients may be apathetic, is reinforced by the principle of target payments which are made only when doctors have ensured a certain proportion of their patients accept certain beneficial procedures. This has led to selective removal of costly non-compliant patients from GP lists and poses a real dilemma when target income may be in jeopardy and the doctor-patient relationship has a more highly developed commercial component—as the patient can choose the doctor so the doctor can choose the patient, but should this be a commercial decision?

It is ironic that this diminution of personal responsibility should arise out of reforms that are intended to move accountability to every patient interface with health care. Whilst increasing the responsibilities of the doctor, the reforms do not generate a concomitant increase in patients' responsibility for their own health care. To that extent they demean the professionalism of medicine and the doctors are obliged almost to force their services onto some non-compliant patients when the very essence of a profession is to provide an expert opinion and service when requested.

In the reformed NHS it is easier to change doctors and at first sight this seems an attractive idea and is clearly consistent with the model of the market place where the best business attracts the most customers. However, bearing in mind the professionalism of medicine and the provision of an expert opinion, it is important to note the customer is not always right and to give in to customer expectation is not necessarily good medicine—the popular doctor may be the one who is lavish with over-the-counter preparations such as cough bottles, or with antibiotics when not indicated, or with sick notes for the slightly unwell.

Additionally, patient choice is affected by the relaxation of the guide lines on advertising but will the best practices or the best advertised practices prosper—and what is the Christian contribution to this debate which generates questions on honesty, on freedom of information, on overt professional competition, and on the use of resources?

TIME FOR PATIENTS

The reformed NHS obliges GPs to spend more time with increasing bureaucracy and administration and this increased attention to paperwork is despite delegation of non-clinical and paramedical functions. The prediction of the reforms is that the successful GP will attract more patients and consequently will have less direct time for patients—but time with the doctor is the consumer's top priority (*Which?* 1991).

The pressures on the doctor's timetable are likely to increase the stress amongst doctors so that (even!) Christian GPs may find it more difficult to be 'nice to patients'. 'My concern for people does not lead me to a position where I believe we should be at their beck and call for trivia night and day' (*CMF Journal*, 1991).

PINCER JAWS OF NEW RESPONSIBILITIES

The NHS under reformation is placing GPs in an uncomfortable position caught between the pincer jaws of new responsibilities—on the one hand, the transfer from patient to doctor of certain personal responsibilities and, on the other hand, the transfer from NHS management to doctor of responsibility for health care budgeting. It is crucial that central government maintains NHS funding at a realistic level and thereby continues to accept its share of responsibility for our Health Service.

Whilst it is self-evident that there is no free lunch at the health care table, we need to know that the seats are not occupied by those who shout loudest in the queue at the door—there always seems to be a queue. We need to know that, in this restaurant, the waiters attend to the needs rather than the wants of their guests—we need to know that the management earns a profit from good, not cheap, service—and we need to know that the hungry are not fed on crumbs that fall from the table.

WHICH? Doctor, Doctor. October 1989 481–485.
Coulter, A: Fundholding general practice, *BMJ* 1992: *304* 397–398.
Department of Health and Social Security. Management arrangements for the reorganised NHS. London: HMSO, 1972.
Whitehouse, C: Justice—for whom? *J. Christ. Med. Fellowship*, 1989; 4–7.
Glennerster, H. Matsaganis, M., Owens, P. *A Foothold for Fundholding*; King's Fund Research Report No. 12. 1992.

Elizabeth Kristol

PICTURE PERFECT: THE POLITICS OF PRENATAL TESTING

During the past two decades, prenatal screening for fetal defects has become a standard part of nearly every pregnant woman's medical care. Tests conducted during the first half of pregnancy are designed to detect a wide range of genetic and other disorders, and to give women the option of obtaining abortions if defects are diagnosed. Some people have heralded this development as a breakthrough in the age-old war against disease. Others regard it as more than that: a tool to improve society. Modern birth control methods, the argument goes, brought us quantity control; the addition of prenatal testing offers a system of quality control. For the first time in history, parents are able to customize, albeit in limited ways, the kinds of children they bring into the world.

Prenatal diagnosis may be a routine procedure, but it raises a number of troubling issues. While the women who avail themselves of the tests are usually worried about their children's health, the political, legal, and medical communities have their own reasons for encouraging large-scale screening for fetal defects. Unbeknownst to most prospective parents, moreover, scientists are still debating the safety of the most widely offered screening tests. The ethical issues raised by prenatal screening are even touchier.

Prenatal testing is eradicating illness in a whole new way—preemptively. In so doing, it is imperceptibly altering the pattern of disease in this country. It is a changing society's fundamental attitudes toward parenting, toward sickness, and toward social responsibility. It is even influencing women's notions of childbirth, medicine, and motherhood.

The most common form of prenatal testing is ultrasound imaging, which uses sound waves to produce a picture—or 'sonogram'—of the fetus. Today, more than 80 percent of all pregnant women in the United States receive a sonogram during their pregnancy. Women deemed at 'high risk' for giving birth to a child with chromosomal abnormalities are also offered amniocentesis, a procedure in which a needle, guided by ultrasound, is inserted into the uterus and withdraws a small amount of amniotic fluid for cell analysis. Amniocentesis is usually done between the sixteenth and twentieth weeks of pregnancy. Women may also opt for the somewhat riskier procedure of chorionic villus sampling (CVS), which is usually done between the tenth and twelfth weeks, or earlier on an experimental basis. CVS removes a small amount of chorionic villi (hair-like fringes of the placenta) for analysis, either by using a catheter to pass through the cervix to the womb or by inserting a needle into the abdomen.

Since CVS and amniocentesis are invasive procedures that can harm both the mother and the developing fetus, researchers have long sought a method of testing that cannot endanger mother or child. In the early seventies scientists discovered that high levels of alphafetoprotein (AFP), which is usually leaked from the fetus into the mother's bloodstream in very small quantities, could indicate the presence of neural-tube defects such as anencephaly (incomplete development of the brain) and spina bifida (malformation of the spine), defects that affect one to two in every 1,000 live births. In 1983 it was discovered that an unusually *low* level of AFP in the mother's bloodstream was a possible indication of Down's syndrome. A simple blood test for AFP is frequently offered to women—regardless of age and known genetic risk factors—between the sixteenth to eighteenth weeks of pregnancy. After ultrasound, it is the second most common form of prenatal testing.

Ann Oakley, a historian of maternal medicine, has compared the growing use of ultrasound with that of X-rays, which became popular after the turn of the century and were widely used on pregnant women until it was discovered, a half-century later, that they could cause cancer in children.

More experimental and high-risk diagnostic procedures include cordocentesis (which examines fetal blood drawn from the umbilical cord), fetal skin sampling, and fetoscopy. And what had long been considered the cutting edge of prenatal screening—the testing of embryos before implantation—is slowly becoming a reality. In this

Reprinted by kind permission from *First Things* April 1993, a monthly journal published in New York City by the Institute on Religion and Public Life, 156 Fifth Ave, Suite 400, New York, NY 10010.

method, a couple undergoes in vitro fertilization, and the resulting embryos are genetically analyzed. The healthiest are implanted in the mother, while those bearing signs of genetic defect are discarded. Future forms of testing may push the screening process still earlier, before conception has taken place; research is already underway into the testing of oocytes before fertilization.

These experimental forms of genetic screening are clearly controversial. But even the most common forms of prenatal testing are open to dispute. Despite the matter-of-fact manner in which physicians offer the tests to their patients, their safety has never been scientifically established. Ultrasound, for example, which doctors present as a thoroughly uncontroversial procedure, is still being contested within the medical literature. A classic example of a 'creeping technology', ultrasound in pregnancy has never been subjected to a large-scale randomized controlled trial to assess either its safety or usefulness. Ann Oakley, a historian of maternal medicine, has compared the growing use of ultrasound with that of X-rays, which became popular after the turn of the century and were widely used on pregnant women until it was discovered, a half-century later, that they could cause cancer in children.

Amniocentesis and CVS do pose known dangers, and a physician is supposed to discuss these with the patient at the time the tests are offered and have her sign an informed-consent form. There is a miscarriage rate of 1–2 percent following CVS. The procedure also carries a small risk of uterine infection. In addition, recent studies in the United States and abroad have linked CVS to a number of birth defects, including missing or stubby fingers and toes, small tongues, underdeveloped jaws, and, in some instances, missing limbs.

The FDA regulates the energy output and manufacture of ultrasound devices, but there is no licensing or testing of those who operate the machines. Because of variations in scanning conditions and tissue properties, moreover, doses cannot be measured exactly; an NIH consensus conference on ultrasound concluded that 'there are no data on the dose to either the mother or the fetus in the clinical setting'. The participants also noted that numerous animal studies suggest that exposing a fetus to ultrasound can affect prenatal growth, although there is considerable debate over whether the energy levels used in animal studies can predict the effect of lower levels of energy on humans.

The controversy surrounding ultrasound centers on whether the benefits of its use during routine pregnancies exceed its unknown long-term effects. Prenatal ultrasound is primarily used to verify conditions that the doctor or patient already suspects: it double-checks a diagnosis of pregnancy, establishes the age of the fetus, and confirms conditions—such as ectopic pregnancy, multiple pregancy, or fetal death—that the doctor has deduced from the patient's symptoms or the results of a physical examination. It may also reveal previously undetected fetal diseases or structural disorders in the mother. American and European researchers have repeatedly tried to determine whether the knowledge gained via ultrasound leads to a healthier baby, yet studies evaluating the impact of ultrasound on such key measurements as perinatal morbidity and mortality, birth weight, and Apgar scores (tests conducted immediately after an infant's birth) have failed to establish any statistically significant effects.

The American College of Obstetricians and Gynecologists, following the formal position of the American College of Radiologists, has shied away from endorsing 'routine' prenatal ultrasound. But in all its literature ACOG simply assumes that obstetricians will offer ultrasound as part of standard prenatal care. As one editor of an obstetrics journal wrote: 'Although ultrasound screening is not absolutely necessary for routine prenatal care, I think its use as a screening examination in early pregnancy is here to stay'. It is left to the rare critic, such as Stephen Thacker of the Centers for Disease Control, to make the obvious point that 'the acquisition of more information and the clinical impression that a procedure is beneficial do not necessarily lead to better outcomes'.

Amniocentesis and CVS do pose known dangers, and a physician is supposed to discuss these with the patient at the time the tests are offered and have her sign an informed-consent form. There is a miscarriage rate of 1–2 percent following CVS. The procedure also carries a small risk of uterine infection. In addition, recent studies in the United States and abroad have linked CVS to a number of birth defects, including missing or stubby fingers and toes, small tongues, underdeveloped jaws, and, in some instances, missing limbs.

Estimates of the possibility of miscarriage following amniocentesis range between .5 and 1 percent. Other documented long-term risks to children tested by amniocentesis include breathing and orthopedic problems, particularly club foot. There is also a possibility that the needle may come into contact with the fetus; one Canadian study discovered needlemarks on six out of ninety-one infants whose mothers had the test. On rare occasions, deformities may result from a tap that depletes the amount of amniotic fluid to a dangerous level.

In both CVS and amniocentesis, an initial tap may prove unsuccessful. The doctor may fail to draw enough

fluid, he may obtain urine instead of amniotic fluid, or cells in the sample may fail to grow. In such instances, the procedure may have to be repeated, which compounds the risk to the patient.

How is it that perfectly healthy women may find themselves having a series of medical tests, some of which pose distinct risks to themselves or their children? The typical pregnant woman would be disturbed to realize that a good deal of the testing that goes on is motivated by factors that are, at best, tangentially related to her well-being or the health of her child.

The use of AFP tests has a peculiarly non-medical history. Both ACOG and the American Academy of Pediatrics urged the FDA not to approve early release of AFP test kits in the late 1970s. They noted that in order to detect enough cases of open spina bifida and anencephaly the tests would necessarily have a high false-positive rate—about fifty false positives for every true positive. They recommended that the FDA make its release contingent on laboratories' ability to coordinate follow-up tests to weed out false positives, a crucial concern in a test parents may rely on in deciding whether to continue a pregnancy. But when the FDA went ahead and approved the marketing of the kits without these restrictions, ACOG's legal department promptly issued a liability 'alert' to its members, urging all obstetricians to offer the procedure to their patients. This, it said, should place the doctor in the 'best possible defense position' in the event of a birth defect.

How is it that perfectly healthy women may find themselves having a series of medical tests, some of which pose distinct risks to themselves or their children? The typical woman would be disturbed to realize that a good deal of the testing that goes on is motivated by factors that are, at best, tangentially related to her well-being or the health of her child.

The momentum generated by this single recommendation—inspired by law rather than medicine—was powerful. To offset the inaccuracy of AFP tests, ACOG developed a rigorous protocol for obstetricians. If AFP levels are unusually high, for instance, doctors are urged to repeat the test. If the second test also comes back positive they are to do an ultrasound to determine the reason for the elevated AFP level (such as multiple pregnancy or inaccurate assessment of fetal age). If that is inconclusive, they are to advance to amniocentesis. If that is abnormal, they are to perform a high-resolution ultrasound. With each subsequent test, there is an increased chance that any number of anomalies, slight or severe, may be detected. Thus, a patient who follows her doctor's suggestion to undergo testing for neural-tube defects might find herself, a few weeks down the line, being counseled to contemplate an abortion for a variety of lesser disorders for which she had no original intention of seeking testing.

Like the medical community, the public health sector has its own reasons for promoting widespread prenatal screening. The U.S. Department of Health and Human Services has announced a goal of screening at least 90 percent of the U.S. population 'for fetal abnormalites', an objective that 'will be measured by tracking use of maternal serum alphafetoprotein screening tests'. The HHS report that explains this goal states that 'current ACOG standards recommend that MSAFP screening be offered to all patients'—without noting that this was a legal, not medical, recommendation. Likewise, the California Department of Health, as part of its ambitious statewide screening program, requires everyone who offers prenatal care to inform pregnant patients of the AFP test in an effort to detect greater numbers of potential birth defects. The fact is that governments on both the state and national level have considerable interest in being able to point to reductions in disease. And morbidity and mortality rates are key expressions of a region's standard of living.

When most people hear of 'reducing illness', they usually think of providing greater access to health care or developing new treatments for disease. Public health experts, however, frequently boast of reducing illness by means of prenatal diagnosis and abortion. The highly influential 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research asserted that 'genetic screening and counseling' may be used 'to contribute to the public health goals of reducing the incidence and impact of inherited disorders'. Similarly, an article heralding the 'Decline of Down's Syndrome after Abortion Reform in New York State' boasted that 'in 1975, terminations resulted in abortion of one-quarter of the expected case of Down's syndrome in upstate New York and one-half of the cases in New York City. . . . [I]t appears that abortion reform has become an effective measure to reduce the incidence of severe mental retardation'. In England, the journal *Prenatal Diagnosis* reported one regional study in which abortions after a diagnosis of neural-tube defects led to an 86 percent reduction in the birth of individuals with these disorders. The authors concluded that 'the success of the program in medical terms is apparent'.

Policymakers and medical experts are under pressure not only to achieve noticeable improvements in health but also to reduce soaring health care costs. Widespread prenatal screening followed by abortion for fetal defects would accomplish both of these objectives. The motivation to reduce costs also helps explain the long-standing emphasis on preventing the birth of children with Down's syndrome, a disorder that is more financially costly to society—accounting for about 15 percent of the institutionalized mentally retarded population—than it is personally costly to its victims. (There are certainly other

disorders and diseases that cause greater pain and discomfort.)

In the 1950s and 1960s, when studies seemed to indicate that more than half the children with Down's syndrome were born to mothers over the age of thirty-five, women over thirty-five were urged to have amniocentesis. When two decades of screening and abortion of Down's fetuses in this age group failed to have a significant impact on the national Down's syndrome population, new studies were undertaken. These revealed that only about 20 percent of Down's children are born to women over thirty-five, and that in many cases (nearly a quarter, according to one study) the father may be the source of the extra chromosome that causes the disorder. By itself, then, amniocentesis of women over thirty-five would not do the trick. The discovery that Down's syndrome could also be detected by the AFP blood test, which is safe enough to be given to all pregnant women, was therefore regarded as a major breakthrough.

There has been no shortage of arguments to eliminate the ill or disabled before they become a financial burden to society. In a survey of British obstetricians in the late 1970s, researcher Wendy Farrant discovered that two-thirds of the respondents rated 'savings in costs to society of caring for people with disabilities' as an important benefit of a national screening program for neural-tube defects; 13 percent agreed that 'the state should not be expected to pay for the specialized care of a child with a severe handicap in cases where the parents had declined the offer of prenatal diagnosis of the handicap'. More recently, the British Royal College of Physicians recommended a nationwide program of prenatal screening on the grounds that cost-benefit analysis showed that 'it is cheaper to screen and counsel the whole population than it is to treat affected children who would otherwise be born to unprepared couples'.

Medical cost-benefit analyses are startlingly coldblooded. Studies feature graphs comparing the costs to society of a disabled child with the expense of testing and abortion. Articles debate the appropriate discount rate that should be used in calculating the lifetime costs to the state of caring for a disabled individual. One recent study, which noted the growing cost of providing services for mentally handicapped young adults, lamented the increase in the number of patients with Down's syndrome—an increase the authors attributed to medical advances that have allowed those with Down's to live longer and healthier lives. Debate has surfaced within the cystic fibrosis community over whether advances in the comfort and lifespan of individuals with CF outweigh earlier arguments favoring abortion of fetuses diagnosed with the disorder.

Crucial to all the discussions, reports, and studies supporting prenatal testing is the assumption that women will have abortions if fetal defects are detected. The hard truth is that there are still very few conditions that can be treated in utero. Hospitals will occasionally do fetal blood transfusions or perform surgery for urinary tract obstruction, and drug therapy is useful for treating some metabolic diseases. Experimental research in the area of gene therapy, the replacement or correction of a defective gene in the fetus, would open up the possibility of new forms of prenatal treatment. For the foreseeable future, however, the chief purpose of prenatal diagnosis is to give parents the opportunity to abort a fetus diagnosed with a disorder. It is telling that research in the area of prenatal diagnosis is overwhelmingly concentrated on finding ways to diagnose conditions in the first few months of pregnancy, when abortion is a simpler and safer procedure, even though information about the fetus is much richer later on.

Yet the 'A' word is almost never mentioned in the screening literature. When allusion to the subject is unavoidable, it is glossed over with an extraordinary amount of euphemism. This is the case even in medical journals, where doctors are addressing one another rather than pregnant patients. Physicians refer to 'screening and its sequelae'. Pregnancies are 'terminated', 'selectively terminated', or, most bewildering, 'interrupted'. Parents who receive news of a fetal disorder are urged to 'choose a reproductive option', 'decide the disposition of their pregnancy', or, simply, 'intervene'. In discussing abortion procedures, physicians refer to 'permanent asystole' or 'mechanical disruption of the fetus' rather than fetal death. The word 'amniocentesis' often serves as a stand-in for testing-plus-abortion; one genetics textbook states, 'If all mothers of thirty-five years and over had amniocentesis then this would reduce the incidence of chromosomal disease by 30 percent'. Many British physicians take recourse in acronyms, referring simply to 'TOP'—termination of pregnancy.

Physicians refer to 'screening and its sequelae'. Pregnancies are 'terminated', 'selectively terminated', or, most bewildering, 'interrupted'. Parents who receive news of a fetal disorder are urged to 'choose a reproductive option', 'decide the disposition of their pregnancy', or, simply, 'intervene'. In discussing abortion procedures, physicians refer to 'permanent asystole' or 'mechanical disruption of the fetus' rather than fetal death.

Much of this coyness can be explained by political expediency. A technical bulletin on screening issued by ACOG, a group that presumably would rather be identified with babies than abortion, never mentions the 'A' word, but recommends that 'supportive or therapeutic services appropriate to the decision should be made available'.

The report of the 1983 President's Commission on genetic screening is, for obvious political reasons, a masterpiece of double-speak. When the report discusses screening for Tay-Sachs disease, abortion is nowhere mentioned but everywhere between the lines. Prenatal testing of the fetus, says the report, 'has provided carrier couples with an option that did not exist previously. In the past, couples who had a child with Tay-Sachs disease often found the 25 percent risk of having another affected child to be unacceptable, and decided therefore not to have any more children. Prenatal screening for Tay-Sachs has meant the continuation of countless pregnancies and the conception of hundreds of infants who would otherwise not have been born'.

The Commission also refers to the inevitable tension between the 'public health goals of reducing the incidence and impact of inherited disorders' and 'the special place accorded to the right of individuals to obtain and use screening information as their personal values dictate, whether or not their decisions result in a *reduction in genetic disease*' (emphasis added). The only occasions where the Commission report actually uses the term 'abortion' is when it wishes to capitalize on its pejorative sense; in its discussion of sex selection, the report straightforwardly condemns the use of prenatal diagnosis 'to abort a fetus of the unwanted sex'.

While many pregnant women welcome the choices prenatal testing has given them, others are ambivalent, have misgivings, or have simply not given the matter much thought. Yet the pressures to be tested are powerful. The most obvious pressure comes from the context in which tests are offered. Studies show that even women who have reservations about screening find it difficult to decline tests when their obstetricians suggest them. In one survey, about a third of the women who had already agreed to be tested 'had wondered if it was right to perform a kind of quality control of the fetus'.

In the doctor's office and in the many popular books available on pregnancy and childbirth, there is an assumption that reasonable and enlightened women will naturally want to make use of new screening technologies. The 1983 President's Commission on genetic screening is typical in describing prenatal testing and carrier screening (the testing of couples before conception to determine whether they carry a genetic defect) as enhancing a woman's choices. 'Genetic screening and counseling are medical procedures that may be chosen by an individual who desires information as an aid in making personal medical and reproductive choices', it says. 'Professionals should generally promote and protect patient choices to undergo genetic screening and counseling . . .'.

Politicians and pollsters have long known that the words 'information' and 'choice' are powerful ones for Americans—especially for women. Barbara Katz Rothman, a sociologist at Baruch College in New York has observed that we are raised to welcome all offers of both: 'If there is information to be had, and decisions to be made, the value lies in actively seeking the information and consciously making the decision. To do otherwise is to "let things happen to you", not to "take control of your life" '. Women who reject screening are regarded as 'turning *away* from the value of choice, and even more profoundly, turning away from the value of information'.

Doctors, however, don't have to live with the anxiety generated by testing and the gathering of information; patients do. Yet physicians and women's health advocates repeatedly insist that the best reason for women to undergo prenatal screening is for 'the reassurance it almost always brings'. This is a strange assertion. Certainly, worrying is a natural part of any pregnancy: Can my body do all the things necessary to carry the baby to term? Will the baby be healthy? Will I be a good parent? Such free-floating concerns have always plagued women. But in the past few decades, the normal anxieties of pregnancy have been inflamed by a highly specific set of specters—specters prompted less by genuine health threats than by the promotion of certain tests.

Women have been trained to concentrate their anxieties on Down's syndrome for the simple reason that they are offered tests for it. But they are offered tests for Down's, not because the risk is personally high for them, but because the public health sector has a powerful interest in reducing the number of citizens who may end up requiring government support. Major research efforts have therefore been concentrated on screening for Down's, one of the few forms of mental retardation whose cause is known.

Because there is a test for Down's syndrome, for example, women over the age of thirty have been bombarded with articles about the risks of having a child with Down's; many women can chant the statistics for each age category. To look at this situation from afar, one would assume that women today are at increased risk of giving birth to a child with Down's, or that Down's syndrome accounts for a majority of birth defects or, at least, a majority of cases of mental retardation. In fact, Down's syndrome accounts for only a fraction of all birth defects (including mild retardation) and only a quarter of the cases of serious retardation, which can be caused by a number of unpredictable genetic factors as well as trauma during the birth process. Similarly, the other chromosomal abnormalities, fetal infections, neural-tube defects, and blood and metabolic disorders that can

currently be diagnosed before birth do not begin to exhaust the universe of possible defects.

Women have been trained to concentrate their anxieties on Down's syndrome for the simple reason that they are offered tests for it. But they are offered tests for Down's, not because the risk is personally high for them, but because the public health sector has a powerful interest in reducing the number of citizens who may end up requiring government support. Major research efforts have therefore been concentrated on screening for Down's, one of the few forms of mental retardation whose cause is known.

Displaced anxiety can lead to artificial peace of mind. In the current climate of testing it is all too easy for prospective parents to forget that illness can befall a baby at any time during pregnancy and delivery, or after birth, and that the majority of birth defects are undetectable and unpreventable. Yet, as obstetricians will be the first to admit, many women who receive a negative result on a prenatal test seem to feel that they are in the clear. This false sense of security can make an undiagnosed birth defect or subsequent childhood illness all the more difficult to handle.

Pressures to undergo testing are invariably followed by subtle pressures to abort in the event of a positive diagnosis. While prospective parents may have worked out what action they would take if the fetus is diagnosed with anencephaly or Down's syndrome, they may be unprepared for ambiguous diagnoses, or diagnoses of milder conditions. Most parents do not realise that one in a hundred amniocentesis procedures (and an even higher proportion of CVS tests) will yield a combination of normal and abnormal cells that make predictions of any kind very difficult. Nor do most parents consider the possibility—present with any medical test—that test results may be switched or misinterpreted. And most parents are unfamiliar with conditions like sex-chromosome abnormalities, which are diagnosed in about one in 290 amniocenteses. Nearly all children born with a sex-chromosome abnormality will have a normal life span. Some may be infertile or require hormonal therapy; some may need special help with schooling or behavioral problems. (So, of course, may many 'normal' children). Yet in one study twenty-five out of forty fetuses so diagnosed were aborted.

Any momentous life change, whether desired or dreaded, seems overwhelming in the abstract. Yet most people do rise to these occasions. The incorporation of prenatal screening into childbearing, however, allows couples' abstract fears and prejudices to override their natural instincts. Comparisons between the attitudes of parents contemplating having a disabled child with those who already have a child with a disability are revealing. Surveys of women undergoing amniocentesis have shown that 62 percent say they would abort for sex-chromosome abnormalities, and 57 percent for blindness or paralysis of the legs. Yet only 20 percent of parents who have children with cystic fibrosis would consider abortion for CF. Clearly, having a personal relationship with an afflicted individual can summon up a host of nurturing instincts that do not come into play in a theoretical deliberation. It is interesting to note that these same parents of children with CF would be far more willing to abort for disorders they had no personal experience with. A similar pattern has been reported in parents of children with Down's syndrome.

In one of the largest studies of what are called the 'psychosocial sequelae' of abortion after prenatal diagnosis, these researchers interviewed eighty-four women and many of their husbands two years after the event. They learned that more than 20 percent of the women still experienced grief and guilt that 'interfered with their mental well-being'. Some of the younger women in the group had been having recurring panic attacks and nightmares. One man had been impotent since the abortion. Ten couples had separated at some point during the two years as a result of the stress the abortion placed on the relationship.

The majority of genetic counselors on hand to advise parents during the testing process pride themselves on being 'nondirective'. They see their goal as providing information and helping patients sort out their feelings. But Angus Clarke, a geneticist at the University of Wales College of Medicine, has become skeptical of such claims of neutrality. In an article examining the use of counseling in his field, he concluded that 'an offer of prenatal diagnosis implies a recommendation to accept that offer, which in turn entails a tacit recommendation to terminate a pregnancy if it is found to show any abnormality. I believe that this sequence is present irrespective of the counselor's wishes, thoughts, or feelings, because it arises from the social context rather than from the personalities . . .'.

Within the medical literature there is a clear assumption that counselors are there, in effect, to help patients through the difficult process of *agreeing* to be tested and *agreeing* to abort in the event of a diagnosed defect. A March of Dimes casebook on genetic counseling uses the phrase 'nonroutine decision' to refer to a couple's choice

to continue a pregnancy after a diagnosis of fetal defect. A booklet Yale University Medical School's prenatal testing unit hands out to couples who have just received a positive diagnosis treats as inevitable the grief that will accompany the decision to abort a defective fetus—and, by implication, as inevitable the fact that parents *will* choose to abort. 'How do we describe the decision to actively end a pregnancy that often has been so joyously anticipated?' The booklet implies that parents should shield themselves from those who will simply 'make moral judgments' and carefully likens the mourning process following an abortion after prenatal diagnosis to the loss of a child through miscarriage or accidental death.

But the fact is that parents *are* responsible for ending the pregnancy, and their reactions to the decision, and to the abortion itself, are all the more intense for that. The medical community has only recently turned its attention to the emotional issues surrounding abortion in these circumstances, and the results suggest that the experience is more traumatic than had been expected—almost always more traumatic than abortion in the event of an unwanted pregnancy.

Studies comparing first-trimester abortion following CVS with second-trimester abortion after amniocentesis show similar levels of grief. But abortions after amniocentesis are more taxing physically and more grueling emotionally. Late-second-trimester abortions usually consist of an injection of prostaglandin into the amniotic sac, followed by labor that takes anywhere from several hours to more than twenty-four hours, culminating in delivery of the dead fetus. In an attempt to help parents come to terms with the loss, many hospitals encourage women to view or hold the fetus after delivery. A photo is often kept on file in case a woman who does not wish to see the fetus at the time of the abortion wishes to do so later on. A small number of women opt for dilation and evacuation procedure, in which the fetus is surgically removed from the womb.

Researchers who have began to study the reaction of parents who abort for fetal defect seem surprised at the extent of emotional distress. One group of researchers reached what one would have thought would be an obvious conclusion—that 'for most women the event had the psychological meaning of the loss of a wanted child'. In one of the largest studies of what are called the 'psychosocial sequelae' of abortion after prenatal diagnosis, these researchers interviewed eighty-four women and many of their husbands two years after the event. They learned that more than 20 percent of the women still experienced grief and guilt that 'interfered with their mental well-being'. Some of the younger women in the group had been having recurring panic attacks and nightmares. One man had been impotent since the abortion. Ten couples had separated at some point during the two years as a result of the stress the abortion placed on the relationship.

Nearly half the couples said that their behavior toward their children had become overprotective, anxious, or irritable. Two couples left their children for six months with relatives. Five men left the interview room 'to hide their tears'. And thirteen couples refused even to participate in the study because the subject was too painful for them to discuss. The researchers observed that 40 percent of the women and 9 percent of the men displayed a 'loss of moral self-esteem produced by the awareness of their own contribution to the pregnancy loss'. Although only 32 percent of the women practiced a religion, 82 percent 'experienced a strong spiritual disturbance'. The researchers speculated that '55 percent of the women and 58 percent of the men were potentially at risk of prolonged or unresolved grief because they felt unable to voice their feelings'.

The survey concluded that, 'while a second trimester termination of pregnancy for fetal abnormality may be physically relatively safe for the mother, it remains an emotionally traumatic, major life event for both father and mother'. Yet the researchers who arrived at this conclusion did not reassess prenatal screening in light of their findings. Instead, they simply criticized the 'post-termination care' the couples received, and urged that those who abort under such circumstances receive more counseling: 'Grief cannot be prevented but may be shortened if couples are given the right tools, in the form of skilled preparatory counseling, to come to terms with it.'

As prenatal screening becomes increasingly routine, disability ceases to be viewed as a random misfortune.

Other criticisms of prenatal testing stress the procedure's potential impact on the distribution of illness in society. The epidemiologist Abby Lippman has warned that since affluent people are more likely to avail themselves of testing and more likely to abort when presented with a positive or ambiguous diagnosis, the wealthier classes may be avoiding illness—such as Down's syndrome and spina bifida—that up until now have always been randomly distributed. This demographic shift may leave the disabled without lobbying clout so crucial to obtaining funding for research and treatment.

But even if a woman had all the reproductive choices in the world—whether to conceive, whether to undergo diagnostic testing, whether to treat the fetus, or whether to abort for a particular condition—she still would not be guaranteed a healthy child. When children are born with disabilities or suffer injuries in childhood, will parents steeped in a culture of screening regard them with resentment? The effect of this culture, Barbara Rothman has pointed out, is that conditionality, rather than acceptance, is built into parental love from the start. Screening for defects is a way of saying: 'These are my standards.

Disability advocates and feminists interested in the social impact of reproductive policies have criticized society's growing role in developing and enforcing quality-of-life standards. Even some feminists who are resolutely pro-choice have trouble with abortion for defect.

If you meet these standards of acceptability, then you are mine and I will love and accept you totally. After you pass this test.' Pediatrics expert Jeffrey Botkin agrees that screening may have a destructive effect on the parent-child relationship, noting that testing raises parents' expectations of their children, rather than encouraging parents to recognize the uniqueness of each child.

Disability advocates and feminists interested in the social impact of reproductive policies have criticized society's growing role in developing and enforcing quality-of-life standards. Even some feminists who are resolutely pro-choice have trouble with abortion for defect. As Harvard's Ruth Hubbard has explained, 'It is one thing to abort when we don't want to be pregnant and quite another to want a baby, but to decide to abort this particular fetus we are carrying in hopes of coming up with a "better" one next time'. Disability groups and feminist supporters fear that when physicians encourage the abortion of fetuses with diseases or disabilities, they are fostering intolerance of the less-than-perfect people who are already born. Anecdotal evidence gives cause for concern: in one study of seventy-three parents-to-be undergoing prenatal screening, 30 percent said they thought screening might encourage negative attitudes toward the disabled; half thought that mothers of disabled children would be blamed for their failure to undergo screening or have abortions.

Angus Clarke has remarked on the poisonous effect of the double standard that govern prenatal screening. Physicians and policymakers, he notes, assume that abortion for sex selection is 'tantamount to a declaration that females are of much less social value than are males. Society is not willing to make such a statement, which would have profound implications for how women are viewed in society, and also for how women view themselves'. Yet there are no restrictions on the patient's autonomy to abort for any disability whatsoever. This, Clarke says, indicates the 'low value that our society places upon those with genetic disorders and handicaps. We draw some moral lines for social but none for genetic termination of pregnancy'.

The President's Commission on genetic screening bears this out. While endorsing testing for disorders and defects, the commission roundly condemns sex selection on the grounds that it is 'incompatible with the attitude of virtually unconditional acceptance that developmental psychologists have found to be essential to successful parenting. For the good of all children, society's efforts should go into promoting the acceptance of each individual —with his or her particular strengths and weaknesses— rather than reinforcing the negative attitudes that lead to rejection'.

Other criticisms of prenatal testing stress the procedure's potential impact on the distribution of illness in society. The epidemiologist Abby Lippman has warned that since affluent people are more likely to avail themselves of testing and more likely to abort when presented with a positive or ambiguous diagnosis, the wealthier classes may be avoiding illnesses—such as Down's syndrome and spina bifida—that up until now have always been randomly distributed. This demographic shift may leave the disabled without lobbying clout so crucial to obtaining funding for research and treatment.

It is not too strong to say that childbearing has, in a profound sense, been transformed. This transformation is not the province of one interest group or another: it is not exclusively a medical issue, a legal issue, an economic issue, or a women's issue. Like many revolutions in medicine and technology, prenatal testing took on a life of its own before its implications could be fully assessed.

As screening becomes increasingly widespread and sophisticated, physicians, policymakers, and the courts will be forced to make judgments about what kind of life is worth living and what kinds of disabilities are too costly to society. Already, parents who undergo prenatal testing are finding that answering life-and-death questions is more difficult than they had imagined. How 'normal' does a baby have to be to continue the pregnancy? Which

is worse, a severe physical or slight mental handicap? Should one abort if there is a 30 percent chance that a genetic disease will be transmitted? Is it worth giving birth to a child who will die at the age of forty? Thirty? Twenty?

Prenatal testing has the potential to raise countless uncharted dilemmas. If parents who choose to abort in the case of a detected defect already have children, how do they explain the sudden disappearance of the pregnancy? Do they tell the children it was a miscarriage, or do they try to explain that the pregnancy was ended because the baby had an illness? Other, more peculiar, situations present themselves when mild or ambiguous disorders are diagnosed and parents choose not to abort. In the case of conditions that may affect growth, sexual development, or level of aggression, Rothman has noted, parents might find themselves locked into a certain perception of their children, always on the lookout for signs of abnormality. Perfect normal childhood behaviour will be scrutinized for manifestations of certain diseases. There is no way to know how this atmosphere might affect a child's development and sense of self. As the ability to detect a wider range of nonfatal genetic conditions becomes possible, these sorts of challenges may become increasingly common.

Testing for birth defects, meanwhile, has crept into the life of nearly every woman of childbearing age, whether she avails herself of it or not. It is not too strong to say that childbearing has, in a profound sense, been transformed. This transformation is not the province of one interest group or another: it is not exclusively a medical issue, a legal issue, an economic issue, or a women's issue. Like many revolutions in medicine and technology, prenatal testing took on a life of its own before its implications could be fully assessed. Like too many revolutions, its destructive social consequences may prove to be both far-reaching and long-lived.

Rothman has also described the daunting problem posed by the detection of late-onset disorders, such as Huntington's disease, that do not manifest themselves until adulthood. If parents know the awful secret that the child probably will not live past a certain age, how will this knowledge affect their relationship with the child? Will they find themselves keeping an emotional distance to protect themselves from future pain? Will they, consciously or unconsciously, skimp on ways they invest in their child—whether in education or in encouragement of talents, hobbies, and other skills?

The decisions raised by prenatal testing are the stuff of moral philosophy. But they put real-life parents in inhumane situations. Moreover, they coarsen our very notions of what is involved in being a parent and what it means to be a responsible member of society. Through the gradual introduction of new forms of technology and testing, the medical establishment and the public health sector have been developing subtle quality-of-life standards and not-so-subtle ways of discouraging the birth of those who do not measure up. Debate on the issues raised by screening, when it does take place, has been confined to a small circle of professional ethicists, legal scholars, and feminists interested in reproduction policy.

BOOK REVIEWS

The Ethics of Diagnosis
Edited by: José Luis Peset and Diego Gracia
Kluwer Academic Publishers: Dordrecht, Boston, London, 1992

This book is a multi-author monograph in a series on Philosophy and Medicine under the overall editorship of Professors Engelhardt and Spicker. The editors of this volume are professors in departments devoted to historical studies in science and medicine in Madrid, Spain.

The excellent Introduction by Professor Engelhardt indicates the main points which are to be discussed more fully in subsequent chapters. Diagnosis is defined as 'knowing truly'; but the author emphasizes that diagnosis is not a purely scientific discipline. It is more than accurate appraisal. It carries with it moral decisions and commitments. The investigations necessary to diagnosis involve cost—both in terms of finance and also in terms of morbidity and even mortality—and these have to be justified. Moreover, diagnosis is strongly slanted towards the recognition of certain categories of disease; namely those that are potentially curable or fatal. There are also other subtle influences at work affecting diagnosis. In some health care systems, there is a difference in reimbursment between two closely related diagnoses. American Medicare, for instance, discriminates thus between 'angina' and 'unstable angina'. There are some diagnoses which are avoided if possible. For example, a patient may be offended by a diagnosis of trichomonas infection, because it is categorized as a sexually transmitted disease. Similarly, a doctor may be reluctant to label a patient as having Alzheimer's disease, because of its gloomy prognosis.

The introductory chapter is followed by a historical review; starting with the ethics of diagnosis in ancient Greek medicine, moving through the early Christian era and the Middle Ages to the contemporary scene, with particular reference to the recognition of the importance of observer bias.

The next section is headed 'Anthropological Interpretations'. It contains a particularly good chapter by Professor Spicker, in which he emphasizes the intertwining of diagnosis and treatment. He rejects the traditional teaching that diagnosis comes before treatment, pointing out that response to treatment often helps to sharpen diagnosis. He also underlines the point made in the Introduction that diagnosis is slanted towards curable or serious disease. To employ the jargon with which this volume is liberally adorned: 'Diagnosis is teleological and intervention-orientated'. This goal affects the choice of investigations. The author makes the point that not only must the physician avoid unnecessary and dangerous investigations, he should also con-

sult the patient's wishes as to how far investigation is to be pressed.

The third section of the book, headed 'The socio-cultural dimensions of medical knowledge', includes an interesting chapter on changing fashions in medical diagnosis.

The fourth section deals with 'Computer augmented diagnosis'. The contributors fully endorse the value and acceptability of the computer as an aid to diagnosis. They also indicate its very real limitations. A computer is only as good as the data which are programmed into it, and its helpfulness is limited by such factors as the patient's faulty memory and reticence, as well as by the ambiguity of language.

The final chapter on 'The ethics of diagnosis in the post-modern world' corrects the widespread concern that computer assistance is a further step in the direction of depersonalized medicine. The author insists that the opposite should be the case. The computer should set the physician free to do what a physician can do best; namely to concentrate on the patient's individual and unique needs.

This is a stimulating and important book. Unfortunately, a number of the chapters are difficult to read. Besides technical philosophical terms like epistemology, ontology and heuristic, there is a fair sprinkling of unfamiliar words—such as stochastic, prescinding, semeiotics, diachromic, referent and factoring—as well as a few—like orality, diadic and obtention—which I was unable to find in my Concise Oxford Dictionary. There is also a sprinkling of misprints.

Aberdeen DAVID S. SHORT

Ethical Practice in Clinical Medicine
William J. Ellos
London and New York: Routledge, 1990

Professor Ellos teaches ethics at Loyola University, Chicago, and he also acts as an ethical consultant in hospital. He has set out to provide a text on virtue ethics 'to be used by the busy health practitioner'. His exposition is illustrated by a number of clinical cases.

The method Professor Ellos has chosen is to give very brief accounts of the views on virtue of Plato, Aristotle, Thomas Aquinas, the philosophers of the Scottish Enlightenment, American Pragmatism and contemporary developments. This approach has several disadvantages. The treatment of each thinker is too brief and selective to give a rounded account of their virtue ethics. Inevitably there is some overlap as, for instance, between Aristotle's account of friendship and David Hume on sympathy. The problems which arise from this kind of coincidence of ideas are not analysed and explained.

The most serious criticisms of the book are that it does not explain what a virtue is, nor does it yield a clear account of how ethical deliberation is undertaken in the light of virtue theory. He regards virtue ethics as being 'a radically pragmatic venture'. Unless the relationship of the moral agent to the principles on which he or she should act is carefully expounded the result is a thoroughgoing relativism. No one reading this book will lay it down realising that while on the one hand the physician should be a virtuous person, on the other hand he or she must act out of consistent principle. For that reason alone the book cannot be recommended.

London HUW FRANCIS

Moral Theory and Medical Practice
K. W. M. Fulford
Cambridge: Cambridge University Press, 1989, h.b. £35.00, p.b. £12.50

There are two major problems in relation to mental illness: first, is the concept of a mental illness valid, and second, is it legitimate to commit mentally ill persons against their wishes for compulsory treatment? Dr. Fulford, who is a psychiatrist at Oxford University, explores these problems using logical or conceptual analysis of the ordinary language use of terms like dysfunction, disease and illness. It is a very closely argued thesis. It will be of interest to specialists in this field, and particularly to philosophers with an interest in the nature of medical practice.

London HUW FRANCIS

ETHICS & MEDICINE

9:2 Summer 1993