

# **HEALTH, RIGHTS AND**

**Edited by  
Peter Byrne**

# **RESOURCES**

**King's College Studies**

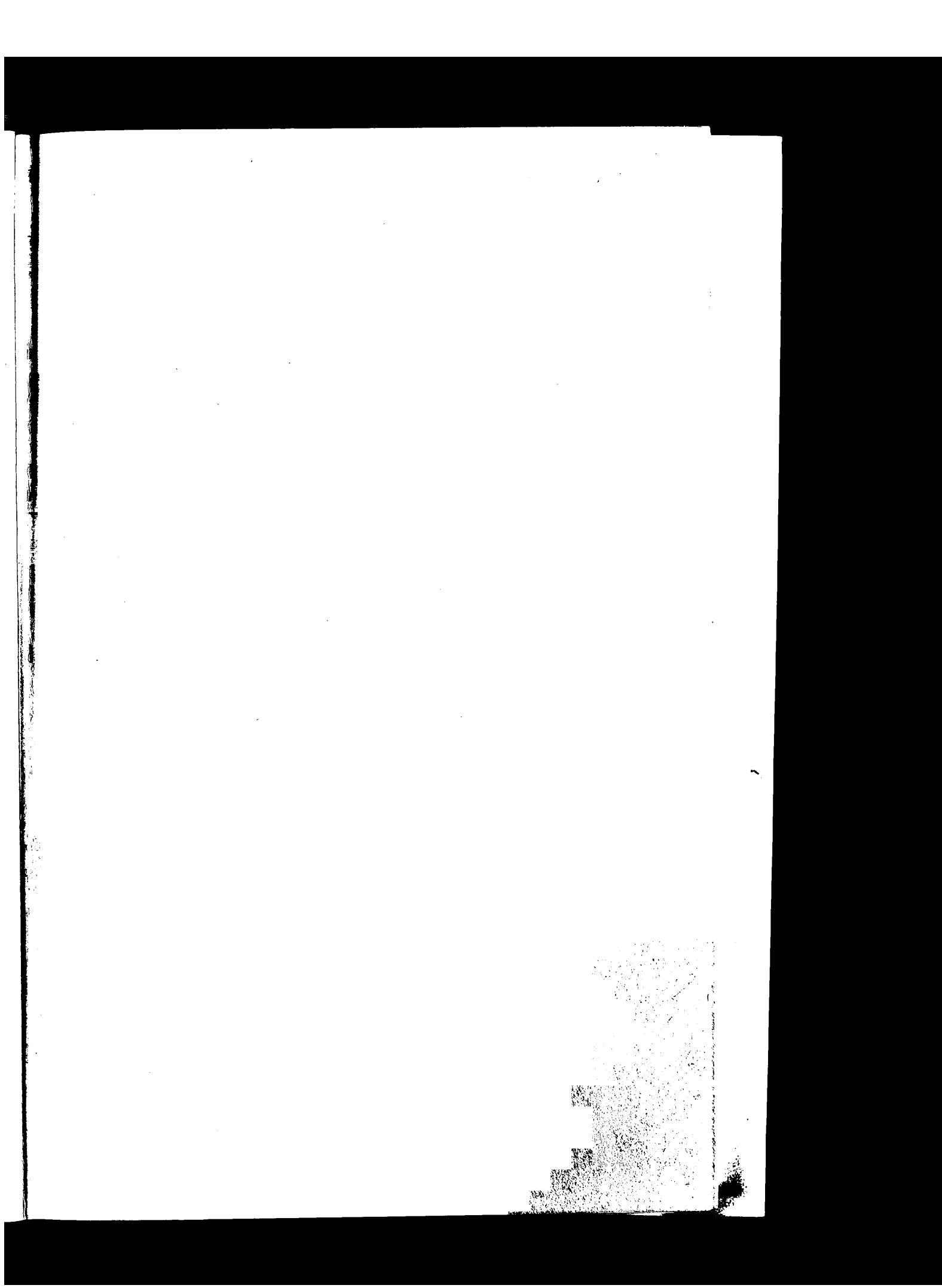
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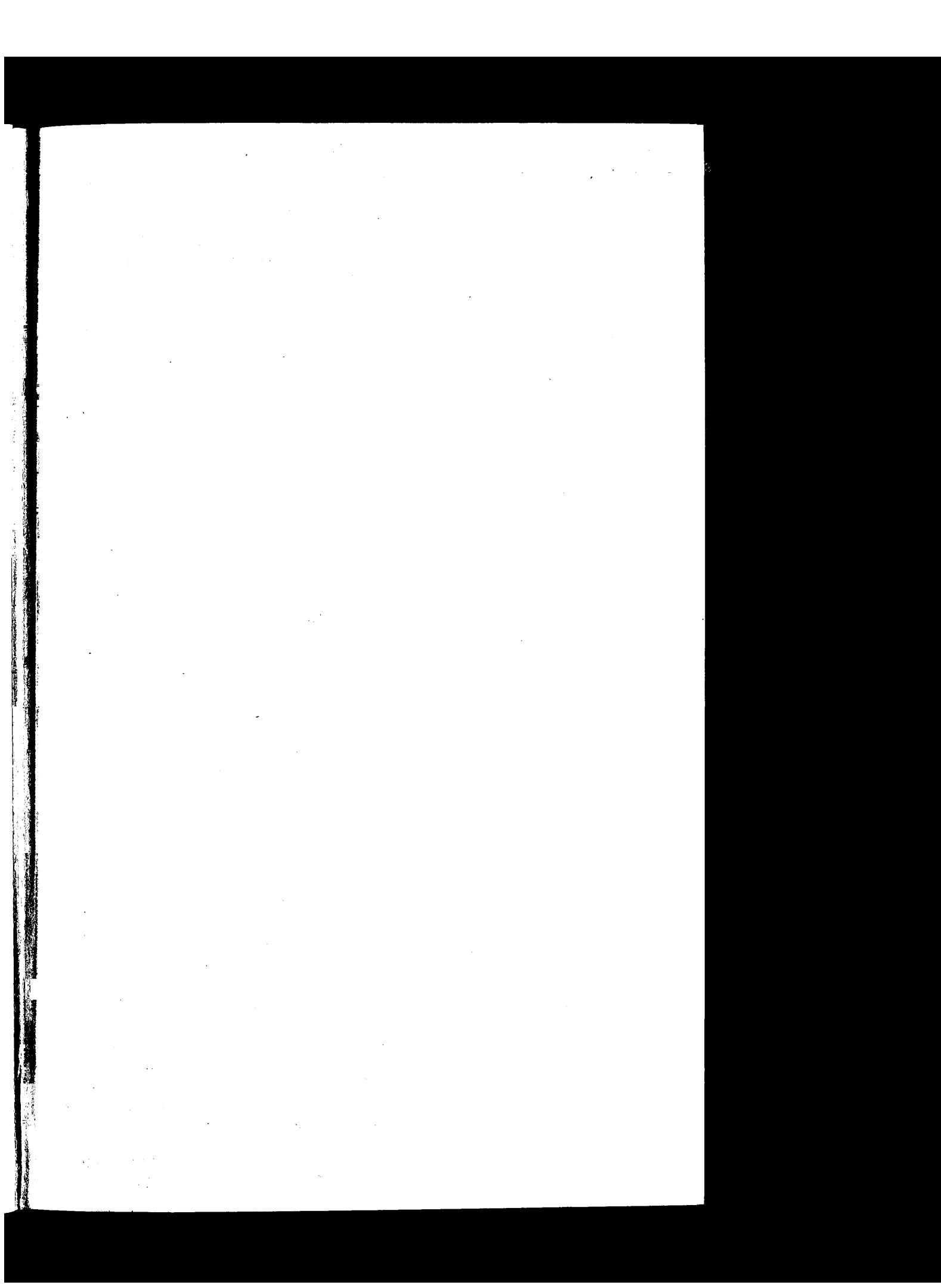
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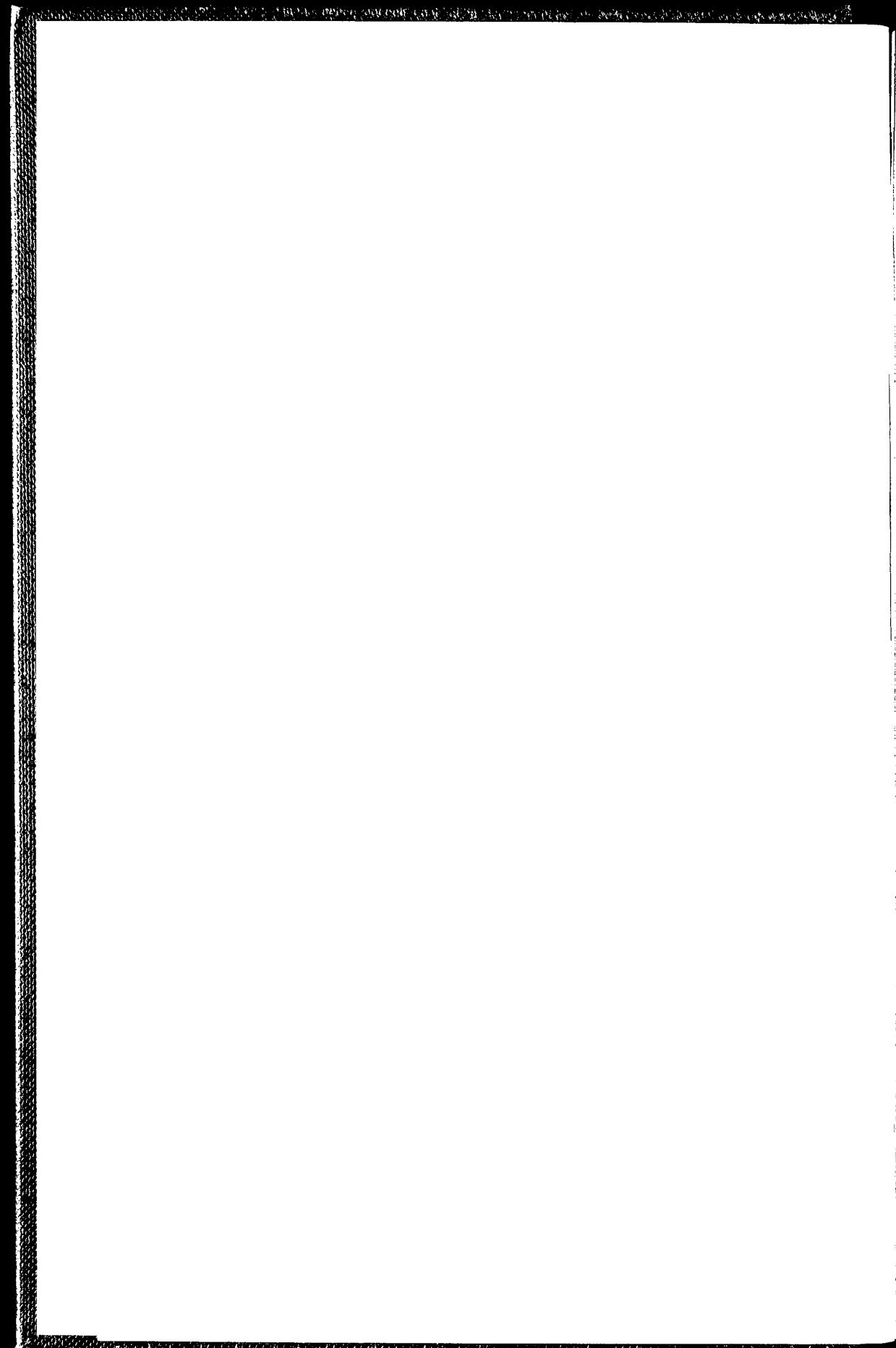
This, the third volume of King's College Studies in medical law and ethics covers the following topics: AIDS; contraception and family planning; human rights and the role of the judiciary in medical law; a national commission for medical ethics; defensive medicine and medical malpractice; the ethics of the allocation of resources in health care; and the legal status of the unborn. Within these diverse themes challenging ideas about rights and resources in contemporary society and medical practice are introduced and explored. The essays summarise existing debates and go on to discuss further these vital issues in medical law and ethics.

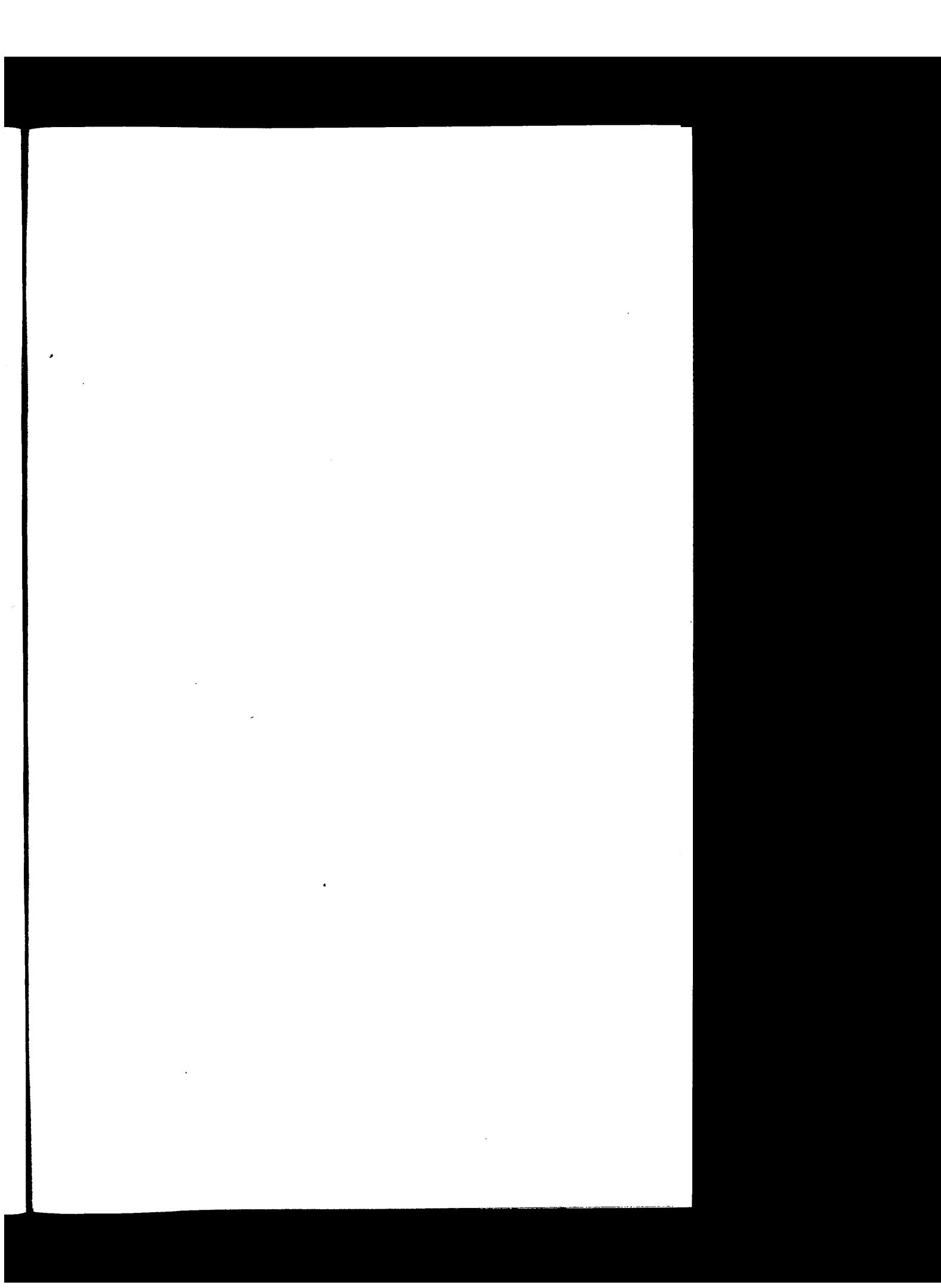
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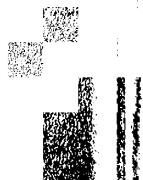




Health, Rights and Resources:  
King's College Studies 1987-8



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# **Health, Rights and Resources:**

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Edited by Peter Byrne

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## PREFACE

The eight papers collected in this third volume of King's College studies in medical law and ethics break new ground while showing continuities with subjects treated in the first two volumes.

The status of embryonic and fetal life is one of the areas of continuity between this and earlier volumes. As I write, yet another attempt is being made to reform English and Welsh law on abortion (on this occasion by Mr David Alton MP). My colleague Simon Lee and John Eekelaar both comment on the legal ins and outs of our responsibilities to the conceptus. What they affirm on this subject should be compared with the philosophical discussion of the morality of 'feticide' by Anthony Kenny in the volume for 1986-7 (*Medicine in Contemporary Society*). John Eekelaar provides an approach to what he terms the 'critical morality' of the status of unborn life which is new to these volumes. It differs from Anthony Kenny's in not pursuing the question of if and when the conceptus attains individual, personal life, and from Simon Lee's in not starting from consideration of the putative rights of the unborn. In one light Eekelaar's mode of argument may be considered complementary to those of Kenny and Lee. Reasoning back to the treatment of the unborn from admitted moral/legal duties owed by parents to infants may simply be seen as an additional source of reflection on the licitness of abortion and on related issues. Eekelaar's arguments offer an important correction to a tendency to simplify consideration of normative questions by focusing on the nature and circumstances of those affected by our conduct to the exclusion of other relevant factors. However, you will note that John Eekelaar tends to offer his approach as an *alternative* to more familiar ways of reasoning, criticising both concern about the

precise status of fetuses as persons and attention to rights as unlikely to shed much light on the important moral and legal questions. No doubt we should be concerned about the lack of clarity in the contemporary rhetoric of rights (scepticism about this rhetoric can be found in my essay on the ethics of medical research in *Medicine in Contemporary Society*). We should also be wary of attempts to settle important questions in ethics and jurisprudence by terminological means. But readers must judge for themselves whether John Eekelaar's precise case on rights and personhood exhausts the matter. Many would think that there are important matters of substance in questions such as 'Is the conceptus a person?' and 'When does it become a person?'. They will consider that with such questions factual, terminological and ethical categories intermingle in crucial ways. They might also consider why we do not pursue the implications of a parent's duties to its born offspring into duties owed to ova: because ova are clearly not instances of individual, personal life. The conceptus must be considered at least a likely candidate for this status for Eekelaar's enquiry to appear worthwhile. They will then conclude that answers to the questions singled out above will contribute significantly to our understanding of the morality and legality of the destruction of fetal life.

AIDS represents a new concern in this series, the volume having been conceived and planned as the epidemic forced itself on public consciousness with the government health education campaign. I try to review the most important issues concerning AIDS raised in the last 12 months which relate to matters of social policy and the evolution of social morality. Roy and Dorothy Porter remind us in their very detailed study that social policy concerning AIDS starts from a background of established social policies toward public health and sexually transmitted disease.

AIDS raises the themes of rights and resources that runs through this volume. In the year of the general election the issue of resources in health care was the target of much political comment. John Harris's paper provides clear statements on two important matters: the advancement of exhaustive, simple criteria to determine valid resource allocation, and the nature and strength of society's obligation to provide sufficient resources for acute medical services in particular.

## PREFACE

John McEwan's full account of issues in modern contraception and family planning reminds us of the importance of preventive and non-acute services. Since many of the recent leading cases in medical litigation have concerned contraceptive procedures it should be especially valuable as background to contemporary medical law and ethics.

Last year (1987) saw the first £1,000,000 award for damages and compensation from an English court in the case of a medical accident. Ian Kennedy's discussion in the 1986-7 volume of 'the malpractice crisis' and Arnold Simanowitz's critical survey of responses to medical accidents in the same volume is here taken further by Simanowitz's review of the alleged dangers of 'defensive medicine'. His conclusion that these are more mythical than real deserves to be taken very seriously indeed.

The new problems of rights and resources surveyed in this volume raise the question of how our society is to structure and shape the development of the ethics and law of medical practice. Simon Lee notes the reluctance of Parliament to legislate for these new problems and the manifold difficulties this reluctance creates for the judiciary. There is a tradition in the UK of leaving much to the ethics that arises from within the medical profession and particularly to the self-regulation provided by the royal colleges. While there is a great deal that is right with this approach, it is apparent from the growing ramifications of problems in medical ethics and law and the perceived increase of resort to the courts to settle such problems that this traditional approach is insufficient. For good or ill the public mind and conscience will not be fully satisfied by the continued reliance on our traditional ways of dealing with - or avoiding - problems in medical law and ethics. Greater direction from Parliament and the DHSS appear to be called for. It is in the context of considering how these institutions should be guided that the suggestion has arisen for a standing national commission or advisory body on medical law and ethics. Professor Alexander Capron's excellent account of how the US versions of such a body have operated should change the nature of the debate on the need for a commission in the UK. We should not be arguing for or against a national commission in the abstract, but be

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considering the matter only in the light of some concrete model of its constitution and *modus operandi*. The debate must descend to details and away from automatic reactions to the *very idea* of such a body.

Peter Byrne

## REVIEW OF THE YEAR

### 1. AIDS: THE ETHICAL, SOCIAL AND LEGAL ISSUES

Peter Byrne

No apologies are necessary for devoting a considerable proportion of this volume to the ethical, social and legal issues raised by AIDS, or for using this introductory chapter to provide an overall review of these issues. Through the amount of comment it has received from press, radio and television, the way in which its significance has been thrust upon every household, and the scale of its threat to public health, AIDS deserves to be seen as one of the major health issues of the present day. A clear indication of the potential size of the AIDS epidemic can be gained from the tally of 870 AIDS cases, with 490 deaths, reported by the DHSS in July 1987. The Department then estimated that another 30,000 people were infected with human immunodeficiency virus (HIV) in the UK (though some sources put the number of HIV-positive individuals as high as 60,000).<sup>1</sup> Within five years up to 30 per cent of these individuals will develop an AIDS condition. Though many of these conditions will be treatable, HIV-infected subjects will continue to develop further HIV-induced infections and will succumb to one in the end. It is possible that over a longer period than five years, say ten to twenty, the percentage of HIV-infected subjects who go on to develop full-blown AIDS will be even greater – perhaps as much as 60 or 70 per cent. At present in this country numbers of diagnosed cases of AIDS and deaths from the condition double every ten months (in the USA they are doubling every twelve). So it is not hard to see from these figures that, if this rate of increase were maintained, in five years we could have 10,000 deaths, 20,000 cases of AIDS

and an astronomical number of individuals who are carrying HIV. Projections of future spread of HIV infection and AIDS are of course difficult to make, for it is possible that the number of potential subjects for the disease will be exhausted if it remains confined to the present risk-groups. Already in the USA, however, there are 30,000 cases of AIDS, with some estimates suggesting that up to 2,000,000 are carriers of the virus. Figures for Africa are greater still. To such reasons for reviewing issues arising out of AIDS may be added the fact that many of them illustrate in a particularly clear way general issues in health care that apply to many other areas of current interest. We shall see this when we examine such matters as confidentiality and resource allocation in relation to AIDS.

The general thread that links the social and ethical issues arising out of the AIDS epidemic is signalled in the opening pages of the invaluable survey of previous responses to major threats to public health provided by Roy and Dorothy Porter in their chapter. This thread is provided by the imperative need to strike a balance between the rights, liberties and well-being of AIDS sufferers (including here all those who are HIV-positive) and the rights, liberties and well-being of members of the rest of society. This general problem is highlighted by two facts. The first is the fatal nature of the AIDS condition itself. This entails that the AIDS sufferer or HIV-infected patient is perceived as presenting a great danger to the rest of society. The second fact is the sense of public stigma and moral iniquity which significant sections of public opinion attach to HIV-infected individuals.

We can say that in general the sick or disabled do not lose their ordinary liberties as citizens merely through the fact that they are sick or disabled. Indeed, we would think that their condition entails that they have claims over the rest of society. Just because they are ill means that duties of care are owed to them by others. Yet the liberties of the ill and the duties of care owed to them may have to be curtailed on occasions in the light of the legitimate concern of society to protect its own well-being. In our own time society's readiness to give this concern priority on certain occasions is demonstrated in the terms of the Public Health (Control of Disease) Act of 1984. This empowers magistrates to enforce compulsory medical

examination and detention in hospital upon sufferers of notifiable diseases. Already some of the clauses (those relating to medical examination, removal to and detention in hospital) have been extended to AIDS patients in the Public Health (Infectious Diseases) Regulations of 1985 – though whether such clauses have ever in fact been used to restrict the liberties of AIDS patients I cannot say.

From the Porters' chapter the reader will see that there is no easy solution either in favour of the individual or society when we come across an instance of the general problem they point to. Some infections raise the question of the balance to be struck between individual and society in a real and profound way. No simple waving of the flag of individual liberty, or appeal to social necessity, will solve it. What we can say is that when this issue of balance presents itself, key issues of medical ethics and law are also going to be raised and will demand solution. In relation to AIDS these issues appear to divide into those of: liberty, resources, confidentiality, screening, duties of health-care providers, the ethics of prevention, and ethical and religious positions affected by the society's response to AIDS.<sup>2</sup>

### Liberty

'AIDS victims should be locked up'. This headline from *The Independent* for 21 March 1987 introduced the demand from a right-wing pressure group that the fundamental and most basic liberties of AIDS sufferers should be curtailed to prevent the spread of the disease. Other, less drastic, restrictions of the rights of AIDS patients than their complete and forcible isolation from the rest of the population will be considered in the sections on confidentiality and screening below. The demands of the 'Conservative Family Campaign' fit into the pattern of hostility and rejection towards those who carry infectious disease displayed throughout history. It is clear from the experiences of AIDS patients that hostility and rejection is frequently all the comfort many AIDS sufferers get from neighbours, employers and friends. Loss of employment, expulsion from housing, social condemnation and even attacks upon the homes of victims of the disease have been regularly

recorded in the past few years. Some of this hostility is no doubt due to the stigma associated with the common perception of AIDS as a condition of those who are 'depraved' or 'corrupt' to begin with. In this respect the casting out of the infectious has been made much easier for the intolerant and vengeful by the fact that many of the early cases in our experience of the epidemic have belonged to groups already shunned or vilified by sections of the community. If we take away such feelings toward homosexuals, drug addicts and so forth, we can see that the medical facts give no ground for depriving the AIDS sufferer of his basic liberties on the grounds of the threat to society presented by him. These facts show that, though AIDS has a high mortality it is not infectious through normal social contact. Ignorance of the facts about how difficult it is to receive HIV infection from another, fear of the mortality associated with AIDS plus the sense of stigma attached to carriers of the disease *explains* but does not *justify* the casting out of the AIDS victim.

There is little reason to deny the AIDS patient the normal liberties of a citizen to work and live among others because he is not a danger to others through normal social contact. The only justification for the widespread casting out of the AIDS sufferer would come from the thought that the habits which may have contributed to his contracting the infection (intravenous drug abuse, homosexuality) themselves amounted to sufficient reason for social ostracism. It would be hard to sustain any argument along these lines. What we have no doubt witnessed is the use of AIDS infection as a means, albeit often unconsciously, of releasing widespread, deeply-felt prejudices toward certain groups, prejudices which antedate the phenomenon of AIDS altogether.

Rather than being concerned to take away a patient's normal civil liberties, we should be more preoccupied with the unwarranted, harsh treatment meted out to those who are facing the trial of highly mortal infection.

### Resources

There is no question that someone presenting at a hospital with AIDS represents a major drain on resources. The average cost

to acute care services from first presentation to death are put at between £15,000 and £20,000. Multiplied by the number of existing and likely future numbers of AIDS patients and we have a considerable drain on an already strained health care budget. And AIDS and HIV infection provide other demands on the public purse: the pursuit of research, the running of screening laboratories, the extra precautions in the preparation of blood products and so on. The government has allocated extra funds to meet the kinds of needs described here. So far as can be ascertained, these extra funds come from the existing health budget and are not additions to it. (As I write in autumn 1987, the Chancellor's autumn budget statement appears to promise a global increase to the health budget partly to take account of extra spending on AIDS.) No doubt there is a case to be made for concluding that an overall increase in health care resources is required for AIDS prevention, treatment and care. The case could be mounted along the lines suggested by John Harris's conclusions in chapter 6 of this book: AIDS, like any major disease, represents a threat to the life and well-being of the citizens of this country but it is the first duty of any government to provide the means of meeting such threats. In practice, however, the resources provided for health care will be finite and this entails that monies devoted to AIDS will to some extent be taken from other existing or future demands. The ethical question concerns whether or how far this should be done. It is tempting to try to answer this and other questions about the distribution of resources by searching for a single criterion of valid resource use which would enable us to reach quantifiable answers to these pressing questions. John Harris's demonstration of the pitfalls in the 'quality adjusted life year' (QALY) version of this ideal should lead us to be wary of approaching the problem in this spirit. A proper approach should direct us towards using resources on the basis of the greatest *medical* need, and while this may lead to no simple formula for answering our questions, it should at least direct us away from judging the social or personal value of the individuals whom we deem it necessary to treat. (This is, I think, fully in accord with Harris's argument.) The scale of the threat AIDS represents to the life and health of this and future generations indicates that it is an obvious area of great medical

need and therefore calls for the diversion of resources to it. From a review of the medical facts two kinds of morals may be drawn. One is that much *can* be done for those who have already developed AIDS. In many cases the immediate threat to life from conditions encouraged by the collapse of the immune system can be thwarted and even beyond this point care can contribute much to those for whom there is no further hope. (There are strong arguments, medical as well as financial, for thinking that care in final stages of the condition should be in a supported home or hospice environment.) We glean a second, obvious moral from the facts about the potential spread of AIDS presented to us by the medical literature: that an exceptionally high priority must be given to devoting resources to the prevention of further infection and to research into vaccination.

The stigma attaching to the AIDS sufferer is relevant to the allocation of resources. We should be wary of thinking that because he is somehow at fault (if he is) in catching the infection, then he has no claim on our resources. Sexual promiscuity or intravenous drug abuse are habits which people need not have acquired; and we may not as a society particularly like them. This cannot be grounds for denying care or what care costs. The thousands who occupy our hospitals and the time of health carers with conditions arising out of alcohol or tobacco abuse are not turned away. The consequences of consistently applying a 'fault criterion' to the use of health care resources would be monstrous and unimaginable.

### Confidentiality

One of the special rights associated with being in receipt of health care is confidentiality from those who provide treatment. It is particularly important in relation to AIDS because of the common experiences of rejection and hostility described above. Arguments for breaching this normal right of patients in the case of AIDS hinge on the fact that it is in no sense an absolute right. We want confidentiality for patients not as an absolute end in itself but because of what it brings or secures – for example a sound doctor-patient relationship or

the preservation of individual privacy. So there is room to ask whether confidentiality should always be adhered to if the ends it promotes clash with other important ends society may have. If respect for the doctor-patient relationship or privacy interferes with the protection of others, as it might in the administration of justice, social policy might rightly place limits on how far doctors are bound to keep information about their patients secret. AIDS might appear to be a prime instance where social policy can give doctors a warrant to ignore the demands of confidentiality. Upon diagnosis every AIDS sufferer or HIV-positive patient is revealed to be a mortal threat to others. Doctors, or society at large, should have the right to reveal a patient's HIV status to those most at risk (that is, the patient's spouse, sexual partner or immediate family) should he show any signs of reluctance to do this himself. The end secured by having the liberty to waive confidentiality is nothing less than the lives of others and this is sufficient to set aside whatever good confidentiality brings.

I find it difficult to fault the argument just offered as a piece of theoretical reasoning, despite the fact that doctors make so much of confidentiality as the foundation of medical ethics and the obvious importance of privacy to AIDS patients. This is because the aim of thwarting a real threat to the lives of others appears overwhelming. However, if we note the reasoning behind the policies described by Roy and Dorothy Porter in the treatment of other sexually transmitted diseases, we see that a pragmatic justification of confidentiality for AIDS victims is readily available. Much can be made of the point that the goal of reducing the risk to others presented by those who are HIV-infected will only be secured if those who are infected are aware of their condition and can change their behaviour accordingly. Known readiness to breach confidentiality will simply result in fewer potential carriers coming forward for testing. The appropriate balance to be struck is not between society's desire to prevent the infected harming others and the infected individual's right to confidentiality, but between the desire to prevent the spread of the disease in general and the desire to protect specified individuals put at risk by the expected recklessness or uncaring behaviour of an HIV-positive individual. This is an important ethical dilemma,

but surely the best *general* policy is to encourage those at risk of carrying the infection to come forward for testing with as little fear of persecution as possible, while promoting a sense of responsibility in them when they do.

### Screening

Screening for AIDS and the spread of HIV infection can take a number of forms and serve a variety of purposes. I shall consider issues connected with screening under three heads: anonymous screening, compulsory screening and screening for employment.

Anonymous screening for the purposes of accurately estimating the spread of HIV infection among the general population has been under consideration by the government's health officers since February 1987 following a suggestion made by Sir Richard Doll. The plan would be to take extra blood for the HIV antibody test from those already giving blood samples for the purposes of hospital admission or treatment. This would be done without patients' knowledge or consent, but completely anonymously so that the results of testing could not be traced back to those whose blood had been used. In this way invaluable epidemiological information could be obtained without harming anyone. For example, pregnant women are routinely screened for syphilis during antenatal examinations and HIV antibody testing on their blood would enable a track to be kept of the spread of HIV among the heterosexual population. This proposal has aroused great controversy. One ground of objection lies in the clear violation of consent involved in anonymous testing. However, it might be urged that the violation of consent in this instance is trivial. Consent in medicine is a requirement designed to protect against unwarranted trespass on the person or unwanted interference with a patient's control over his own interests. Now provided that screening for statistical purposes can remain anonymous, no patient's interests will be adversely affected; the taking of a little extra blood on a normal occasion of sampling is no serious interference in a patient's life. The other main objection comes from the thought that it would be irresponsible for the medical profession to be unable to trace

positive results in tests for HIV status back to patients who need to know this vital information. The point was made by Sir Malcolm McNaughton, President of the Royal College of Obstetricians, when he objected that it would be unethical not to tell a pregnant woman if she was infected with HIV (*The Independent*, 7 February 1987). The charge that anonymous screening would result in a massive failure in the medical profession's obligations toward those whom it was supposed to help might be overcome if anonymous screening were presented as part of a larger process of offering tests for HIV status for those at risk in getting or passing on the virus. If, for example, pregnant women were routinely offered an open test for HIV infection, in addition to their blood samples being used anonymously for statistical purposes, then none would be forced to lose the advantages knowledge of HIV status would bring. Anonymous screening for epidemiological purposes may thus lose its objectionable character if it is but part of a larger effort to offer testing for the spread of HIV.

We have argued that open screening should be freely available to those at risk and those most likely to be spreaders of HIV infection. It is not difficult to list groups who fall into these categories: prostitutes, homosexuals, pregnant women, intravenous drug abusers, haemophiliacs. These and other groups need to know their HIV status. Open screening is non-controversial while it remains voluntary. From time to time we have had requests for compulsory screening, say for all those entering the country from parts of the world where the disease is rife. Fundamental medical facts about the time it takes for an HIV antibody test to produce a result (some two weeks at present) suggest severe practical difficulties in such proposals for forms of compulsory screening. Where would we put the thousands of airline passengers in the meantime? To allow them to roam the country before their result came through would destroy the object of the exercise; those infected may pass on their infection easily in that period. To insist that they should not be allowed into the country without a prior, 'clean' HIV antibody test is also futile: a single night's work between the date of their test and their arrival in the UK could have nullified their HIV negative status. We can note in addition that compulsory screening of any relevant group is only going

to be worthwhile as a measure of social protection if it is linked to readiness to control the behaviour of those screened thereafter. For example, it would make little sense to incur the problems of attempting to force all prostitutes to have regular HIV antibody tests unless society were prepared to introduce some state regulation of the trade whereby those found to be HIV positive would be prevented from practising thereafter. Compulsory screening would have to be part of a significantly larger measure of social control to be effective and to be worth the risk of driving underground those needing help. This suggests that it is a non-starter in a liberal society. The proponent of compulsory screening for people and groups already living in the country should face the onus of proof in demonstrating the worth of the idea, and in particular in explaining why established policy on the treatment of other sexually transmitted diseases (described in Roy Porter's and Dorothy Porter's chapter) should be overturned in the case of AIDS.

A form of compulsory screening which has aroused great controversy is that endorsed by the annual conference of the British Medical Association in the summer of 1987. As a means of protecting medical staff in hospitals some doctors demand the right to test all hospital admissions for HIV status without consent. This would not of course be anonymous screening of the sort discussed above. As well as being a dubious infringement of patient autonomy, it is doubtful if such compulsory testing is lawful, given present law on trespass to the person. (The BMA's council have been advised to this effect – see *The Independent*, 24 September 1987.) Moreover, it is arguable that such screening is unnecessary. If HIV infection can be spread only through injection of infected body fluids or transmission of them via intimate bodily contact, then normal, safe ward or surgery practices should be sufficient to protect hospital staff. It remains to be proved that more is needed. In which case screening for AIDS in hospital should either be anonymous (for epidemiological purposes) or open when done as a necessary part of a patient's treatment or diagnosis. The former need not, I have suggested, be governed by the normal requirement of informed consent; the latter must be.

Given the prejudice AIDS sufferers meet and the fact that

the infection is not passed on through normal social contact, it may seem absurd to countenance the possibility of screening for HIV status in employment. However, some forms of such screening may be acceptable and we should certainly anticipate their adoption. Screening need not be a way of enforcing unnecessary and objectionable employment practices against members of risk-groups (such as homosexuals) but may be a valid means of keeping track of the future health prospects of valuable employees. Health screening in the context of employment is an established fact, perfectly acceptable as a means of safeguarding the interests of an employer where his investment in staff would be put at risk through their unfitness. The safety of the public may also be threatened by employing less than fully fit personnel in certain jobs. HIV testing may be no different as a means of assessing the future fitness of staff than taking their blood pressure or ECG. It will be acceptable, then, where it is a valid expression of an employer's interest in fully fit staff, and not the result of the prejudice or fear which may be mistakenly aroused by HIV-positive individuals. That such screening may be misused is no argument that it cannot be used properly, though in any development of HIV antibody testing in occupational medicine it will be important to offer employees the maximum confidentiality compatible with serving the interests of the employer.

### Health care providers

From what has been said above about compulsory screening for hospital admission, it will be seen that some regard AIDS patients as serious risks to those who must treat them. This *may* be regarded in some quarters as a ground for removing or lessening the duty of care and treatment owed to AIDS patients by members of the medical professions. It is tempting to argue that AIDS sufferers should get that same, high level of commitment and care from health care professionals as those suffering from mortal infections in the past. It is worth recalling in this context the general response from the medical professions to infectious diseases in the 19th century. There can only seem to be a sharp dilemma between what is owing to AIDS sufferers as patients and the rights of doctors, nurses,

dentists and so forth to protect their own health if the facts about the way AIDS can be transmitted are ignored. Much is known about the transmission of HIV and it tends to suggest that HIV is not an easily transmittable infection. The mistaken perception of AIDS patients as highly infectious and the stigma attached to those in the risk groups falsely combine to produce the result that some in need are denied help. Perhaps one of the most important groups who need to be targeted for health education on AIDS is the medical profession.

### The ethics of prevention and health education

There is at present neither cure nor vaccine for AIDS and HIV infection, so it is understandable that so much effort should go into prevention through health education. The way in which this has been done raises issues which connect with those to be considered in the next section where the relationship between AIDS and sexual morality will be discussed. It appears that HIV will be spread through the population primarily via sexual promiscuity and intravenous drug abuse. Any programme of prevention therefore appears to be faced with a dilemma: either it tries to persuade people to abandon these practices or it persuades them to undertake them in a 'safe' way. And this dilemma leads on to an important question: should the common social morality of our society (particularly as it concerns sexual matters) influence the way in which risk-groups are approached by those concerned with public health?

It has been noticeable so far that the public health education campaign has been conducted in a firmly non-moral tone. A sample piece of health education literature such as the then Health Education Council's pamphlet *AIDS: What Everybody Needs to Know* (November 1986) makes no effort to preach and assumes no moral position on the practices it describes. Under the heading 'How can you reduce your risk of getting the virus?' it notes that the more sexual partners a person has the more the chance of infection is increased, and it points to the dangers of drug users sharing needles and equipment. The advice to members of risk-groups to reduce the number of sexual partners they have or not to inject drugs is there, but there is no moral urgency behind it and it is

accompanied with suggestions about how to continue these practices more safely. The great emphasis placed on advice about the use of the condom in sexual intercourse and the trial of issuing free, sterile equipment to intravenous drug abusers has seemed to some to be an abdication of society's responsibility to urge proper moral standards upon those who bring the risk of disease on themselves and others.

How we view this issue will obviously be influenced by our stand on the immorality or otherwise of the practices which increase the risk of AIDS infection. (There is certainly room for argument over sexual promiscuity as we shall note in our next section.) Assuming that we do regard them as deeply immoral there is still, of course, room to argue on pragmatic grounds that health education or preventive measures cannot be based on the premise of the immorality of these practices. For prevention to be effective it has to engage with the behaviour and mores of the risk-groups as we actually find them. If it is based on the explicit premise that their behaviour is immoral they will ignore it. To moralise to those at risk will not change their behaviour (they will not see their behaviour as immoral anyway) and will lose their cooperation in the fight straight away. This argument for a non-moral approach to prevention and education presents the issue as one joined between hopelessly impractical moralising and hard-headed concern to stop the spread of mortal infection. However, this may be to over-simplify matters.

Those who wish prevention and public education to take rather more notice of accepted moral standards can argue that a change in attitudes to the kind of practices that have helped to spread the epidemic offers much better hope of achieving results in the long run. For example, change in attitudes toward promiscuity and casual sex appears to offer greater hope of containment than the mechanics of 'safe sex'. This is not merely a reflection on the effectiveness of condoms (though it is known that in actual use they are nowhere near 100 per cent safe), but also an acknowledgment that the very same casual attitudes toward sexual intercourse characteristic of the promiscuous will be those which encourage lack of attention to hygenic measures and precautions. It may be argued that growth in illegitimacy figures and continued high demand for

abortion is indirect testimony for this conclusion; promiscuity as a cast of mind militates against concern for consequences. Those of this persuasion can argue that there needs to be a new seriousness about sex if prevention of further spread of the epidemic is to succeed. This is why Clifford Longley contended as follows in *The Times*: 'Judeo-Christian sexual morality is emerging as society's fundamental line of defence against the threat of a devastating AIDS epidemic' (12 January 1987).

Fuller discussion of whether the AIDS epidemic is an occasion for reasserting traditional social and sexual morality will be given below. For the moment we can conclude that there are strong practical reasons for ensuring that the message of reducing numbers of sexual partners should be given as loudly and as often as praises for the condom. Fidelity and monogamy can and surely must be sold as vitally important in maintaining the public health. 'Promiscuity is a danger to health' would seem to be a good slogan in the absence of a vaccine for HIV infection. The link between intravenous drug abuse and AIDS is a worthwhile ground for increasing health education on the mortal dangers of all forms of drug abuse. The fact of drug abuse must be a target as well as the type of equipment used.

### Moral and religious positions

So far I have dealt with the issues in medical ethics arising out of the AIDS epidemic. Yet much of the moral discussion generated by AIDS has concerned wider issues in social morality. AIDS has been used by many as a phenomenon which demonstrates the need for society to return to a traditional sexual ethic. It has become ammunition in the continuing debate between moral conservatives and liberals about the value and consequences of the sexual liberation characteristic of modern, Western societies. The Chief Rabbi's comments in *The Times* (27 December 1986) are typical of much that has been spoken and written about AIDS in this connection:

AIDS is the price we pay for the 'benefits' of the permissive society which, helped by the pill, liberal legislation and more 'enlightened' attitudes, has demolished the last defences of sexual restraint and self-discipline, leading to a collapse of nature's self-defence against degeneracy.

The comments of the Chief Rabbi contain a defence of Jewish-Christian teaching on sex and in particular of something which has been described as 'the Western norm'. This may be summed up as follows: 'It is that sexual relationships shall be exclusively heterosexual, and that no sexual activity shall take place outside monogamous unions which are, intentionally at least, life-long'.<sup>4</sup> This norm may be defended without any reference to religion, but it has been specially associated with religion in our society and it has been invested with the authority of revelation. It should be noted straight away that reassessments of traditional sexual morality are not equivalent to expressions of hatred against homosexuals or other minority groups implicated in the spread of the epidemic. To think that homosexuality or promiscuity are vices is not yet to regard those who practise them as worthy of vilification or persecution in any form.

There are clear problems, however, in using the AIDS epidemic to reassert Judaism's and Christianity's social teaching, and strong grounds for supposing that the fact that the spread of AIDS is linked to sexual promiscuity will not by itself prove that this social teaching is correct. There are two major sources of difficulty in using the AIDS epidemic in this fashion. One lies in the fact that the ethic of sexual liberation which is the target of the strictures of conservative moralists has a strong intellectual case behind it. It is not clear immediately how the fact that sexual permissiveness now has important public health consequences (at least until an effective vaccine for AIDS is produced) demonstrates this case to be unsound. The second area of difficulty lies in the grave weaknesses in the customary arguments for the ethic represented by the Western norm. Again it is not obvious that AIDS removes these problems. I shall explore these sources of difficulty in making moral capital out of AIDS in a little more detail.

Those who think that AIDS has placed the final nail in the coffin of sexual liberation must acknowledge the strength and influence of the intellectual case developed in recent years for rejecting the Western norm and the kind of social and moral traditions that go with it. This case is associated with a liberal account of the basis of social and individual morality. According to this account social morality and law ought to rest upon

maximising the liberty of each to pursue his or her preferences. A person's pursuit of his preferences only becomes the concern of social morality and law if it infringes the liberty of others to pursue their preferences. In other words, conduct that harms or interferes with no one else in a tangible way cannot be wrong, even though the majority may find the preferences on which it is based distasteful or repugnant. From this account the conclusion easily follows that there is in fact no such thing as *sexual morality*. There are no species of wrong-doing or restraints on conduct that arise specifically from the area of human sexuality. Moral notions connected with harming others apply to sexual relations. So rape is a form of wrong because it harms others and infringes their liberties. But if sexual behaviour causes no harm to others or violates no one else's freedom then it cannot be wrong. Departures from the Western norm such as promiscuity, sodomy, or prostitution are not wrong in themselves, though particular instances of them may be, should they harm or coerce others. The long list of sexual 'vices' associated with traditional religious teaching on sex is, in fact, no more than an unjustified attempt to impose majority sexual preferences on those who take their pleasures differently. This aspect of the liberal viewpoint is well summed up in the comments of John Harris on voluntary prostitution as a perfectly proper way of earning a living:

If we judge that certain things are so important or so personal that only love, or perhaps conviction, should play a part in our decision to do them, then well and good for us. But if others take a different view we should not object.<sup>5</sup>

The connections traditionally made between sex and love, on the one hand, and monogamy and fidelity, on the other, appear to reflect facts about some people's life styles or choices, but to have no normative implications for the behaviour of mankind in general. It is thus an illusion – based on a mistaken, authoritarian picture of the basis of social morality – to suppose that there is a sexual morality which needs to be consulted when we determine our response to AIDS.

To the strength of the case for a liberal view of sexual conduct we may add the problems raised by the weakness in traditional arguments for the Western norm. It is not evident to

many in our society what the ground may be for applying moral categories to this area of life. The customary basis has consisted either of an appeal to scriptural pronouncements denouncing licentiousness and homosexuality, or of the use of teleological claims about the proper functioning of the sexual organs. In a society which has long since ceased to have any sense of the authority of revelation the first mode of justification will no longer carry much weight. The second moves from premises about the design of the sexual organs for the production of offspring to conclusions about the illicitness of using them for purposes which exclude this. A clear weakness in this way of justifying a traditional sexual ethic lies in the fact that reasoning about designedness to ethical conclusions will only be convincing in the context of an explicit form of theistic belief – the very thing that will make the argument unconvincing in our age. Moreover, the linking of design to reproduction is obviously unconvincing if taken exclusively. Facts about human sexual desire suggest that it is not solely linked to the need to reproduce the species. It is indeed difficult to fit much of the sex life of heterosexual, married couples within a narrow teleology of this sort.

To the difficulties of using AIDS as a way to reassert the traditional Jewish/Christian ethic of sexual relations we can add a further problem. Granted that the rapid spread of AIDS can be shown to be largely the result of sexual practices which liberal thought would clear of their traditional stigma or shame, how does this help to prove that these practices are ethically wrong or that the liberal view of sexual morality is mistaken? The Western norm of chastity before marriage and fidelity within it was never intended as an assertion about what was necessary for the sake of public health, but as a moral claim about the proper form of life for human individuals. If the Western norm is correct as an ethical standard its correctness does not rest on public health grounds. If it is mistaken or questionable, public health considerations will not make it true. Looked at in this light the flood of moral reflection provoked by AIDS is simply a mistake. AIDS does not raise any issues for social morality at all (excluding the narrower issues in medical ethics concerning confidentiality and so forth aired above).

The debate about the proper shape of sexual morality within our society faces us with a choice between some version of the Western norm and a liberal view of the significance of sexual conduct. A review of the issues discussed so far shows that much of the comment on social and sexual morality provoked by AIDS has seriously ignored many of the issues that need to be addressed. It has in effect used the facts about the AIDS epidemic to shortcircuit necessary debate about the relevant moral principles to be applied to sexual conduct. If we follow the presentation of the moral debate in this chapter to this point, the decision we must make about the shape of social morality on sex hinges on at least three important and related questions. 1. Is a philosophy of pursuing individual preference while not harming others an adequate account of human good? 2. If we are to have a richer notion of human good, will the right ordering of sexual relations be an important, component part of it? 3. Are the social consequences of an ethic of individual preference tolerable? (These include the public health consequences created by sexually-transmitted diseases such as AIDS; also the consequences for personal and family life moral conservatives rightly or wrongly associate with sexual liberation – growth in divorce, one-parent families and so forth.) Only by resolving these issues can one who wishes to defend a traditional picture of sexual virtues and vices show how it is relevant to a society where appeal to revelation or a narrow teleology of the human body is unconvincing. The mere fact that there is an AIDS epidemic should not be used to prejudge these three issues.

I cannot hope to resolve the choice about the shape of social morality here, nor can the issues I have distinguished be treated fully. Some brief comment on each of them is offered by way of showing how the steps typically missing from presentations of the conservative case in public comment on AIDS must proceed. I begin with issue number 3. Here it is important for the moral conservative to defend the idea that the public health consequences of current sexual practices *are* morally relevant. In this way the conservative moralist may at least hope to show that AIDS raises the question of the need for a sexual ethic in an urgent form.

There is no reason why a traditional sexual ethic, if it is valid,

should not rest on a variety of considerations which include the health of those who engage in sexual activity. The fact that a practice has harmful personal and social consequences is, on most accounts, likely to be something which bears on its ethical status. A proponent of traditional sexual ethics can hardly be taken to task for thinking that if promiscuity can occasion a major epidemic, this confirms what more recognisably moral reasons show in his view, namely that promiscuity is wrong. The attempt to divorce the public health aspects of sexual behaviour from its ethical aspects also ignores the possibility that health and its maintainance have an ethical dimension and importance. According to the Jewish/Christian moral inheritance, respect for our bodies and health is a religious and moral duty and thus the deliberate mutilation of the body a sin.<sup>6</sup> It is difficult, of course, for the liberal standpoint sketched in this paper to make any great sense of this thought. If someone's personal goals were served by self-mutilation (say, cutting off a limb the more profitably to live the life of a beggar) and no one else were harmed thereby, the liberal would struggle to see what species of wrong might attach to this. However, ordinary moral thought is perhaps closer to religious tradition on this point than to liberal ethical theory. Many might accept that respect for persons entails respect for bodily health and integrity. To respect myself as a person involves respecting my body, for while I live as an embodied being my body is me. If my body is mutilated then I am mutilated. Appropriate reflection on issue number 3 thus leads to reflection on issue number 1: what is an adequate account of human good? The conservative stance on sexual morality must be linked to the thought that sex connects with a larger order of rights and wrongs than is provided by the means of efficiently satisfying my preferences without interfering with the preferences of others. This provides a further stage in the conservative case for seeing the AIDS epidemic as ethically significant: the public health dimension confirms the notion that sexual activity is not an area where personal preferences can be allowed to reign unchecked or which can be given over entirely to private tastes. This is a notion that the conservative must build on in ethically significant ways.

What we have seen so far in relation to the implications for

sexual morality and religion raised by AIDS is that by itself the AIDS epidemic is not a vindication of a traditional sexual ethic. It must be linked to other considerations in favour of the ethics embodied in the Western norm. These additional considerations must rest on senses of 'wrong' or 'harmful' which are richer than that provided by liberal ethical thought and thus take us firmly into issue number 2. Where might we find such richer notions of harm?

We do operate with richer notions of wrong and harm, which do not appear merely to reflect outmoded relics of religious tradition. Consider the earlier example of a person who deliberately mutilates himself. Someone might have good reasons from his own preferences and life-plans for doing this – it may be an act which satisfies someone's preferences without interfering with the preferences of anyone else. Ordinary moral thought will still regard such an act with moral distaste and it is contrary to social policy as enshrined in law to assist in an act of this sort. The richer notion of human good the conservative needs to introduce at this point turns around the idea of respect for persons. Self-mutilation violates such respect because it violates respect for our endowment as embodied human beings. Of an individual who engaged in such conduct we can say in Kantian fashion that he is not treating humanity in his own person as an end in itself, but as a means. This non-liberal notion of human good is also to be found in common condemnation of one who acts so as to stifle his self-development by choosing, say, to remain ignorant as a pig while knowledge and education are readily available. Consider in this context also how we might react to one who voluntarily sold himself into slavery. It is not difficult to imagine how this might best satisfy someone's preferences, but we should still criticise it against the background of a broadly teleological approach to the facts about our humanity and personhood which give us a richer notion of good and harm than that perhaps allowed by liberal critics of the idea of a sexual morality. This richer notion of human good appeals to a, no doubt hazy, conception of what is good for rational embodied, human selves. Individuals may have on occasion reasons arising from the nature of their personal preferences to disregard this good. Where these preferences are not

considered by ordinary moral reflection to be sound reasons for setting aside this good, it is because they are taken to be preferences which dishonour someone as a rational human creature – like the preference for a mutilated body, or for ignorance, or for bondage.

I have so far tried to reconstruct the kind of argument on issues 1 and 3 that those who make moral capital out of AIDS must give us. It is not difficult to see how in general terms these might be applied to the problem of defending a traditional sexual ethic. The appalling consequences that sexual liberation can, at least temporarily, create for public health may be viewed as ethically significant if they are linked to a picture which shows how sexual permissiveness is contrary to our good as rational, embodied selves. The richer notion of human good discussed needs to be applied to sexual desire and conduct.<sup>7</sup>

Sexual desire and conduct will have to be fitted into a portrayal of how rational, human selfhood is to flourish. The argument will start from the importance of sexual desire as a means of realising our nature as embodied beings. In the economy of human nature sexual desire may be linked to bonding. It is nurtured and deepened by love and the moral constraints that go with it. Restraint and fidelity can be argued to be connected with the very nature of sexual desire and the vital relationships of intimacy, bonding and caring that sexual behaviour makes possible. Far from it being true that there is no such thing as sexual morality, the conservative moralist must argue that sexual relationships are moral in their fundamental structure. This is so because through the right character of sexual desire our existence as embodied beings is realised and through the wrong direction of sexual desire we become depersonalised and may depersonalise others. Through the right direction of sexual desire we establish relationships of intimacy which cannot be understood unless moral notions, such as respect and mutual affirmation, are seen as integral to them. Sexual desire, love and the bonding relationships these make possible are not merely moral characteristics of human life in their own right. They are also the foundation of other elements in moral existence because they are at the basis of our existence as social creatures. The bonding between human

individuals mutually affirmed in their love and the natural extension of this in the love between parent and child which grows out of it, together provide one of the most important roots of social and moral existence. Out of this extension of sexual desire into the family grows a sense of responsibility to other persons and to the human past and future on which social life depends. The conservative moralist must show that to treat sexual relationships apart from this ramified moral context is to destroy their point and meaning. He will urge that to regard them as valuable only in being the source of pleasurable sensations, which human beings may properly get in a number of ways according to taste, is to trivialise sexual relationships. The pursuit of sex as a provider of pleasures that end with it must be one of the main targets of the conservative moralist. The pursuit of sex as an end in itself appears to be what lies behind the casual and permissive mores that have done so much to help create the AIDS epidemic.

I have offered a brief sketch of some of the considerations we must be given if we are to accept that AIDS can properly be used to comment on social and sexual morality. My sketch indicates that there may be resources in ordinary moral thought which enable AIDS to be used as part of a reappraisal of contemporary sexual attitudes. I have argued that these resources cannot be *assumed* to exist, but need to be brought to the surface and explored. Only then can we avoid the bland assumption that everyone knows promiscuity to be wrong.

Much of the broader moral comment provoked by AIDS has of course been connected with homosexuality. AIDS has clearly been welcomed in some quarters as long-awaited, external confirmation that homosexual practices are evil. Even if we do accept that AIDS is an occasion for seriously re-examining contemporary sexual mores, we should take a very long pause before concluding that it proves anything about homosexual sex. Granted that in Western countries AIDS infection is particularly rife among homosexual men, there are two reasons at least why this fact is of limited ethical significance. One is that it may be no more than extraneous reasons that has produced this association between AIDS and homosexuality. It remains to be proved that the types of sexual intercourse indulged in by homosexuals are especially likely to

cause the spread of the infection – this despite the fact that the health education literature used in this country continues to insist that anal intercourse is particularly dangerous.<sup>8</sup> The facts show that in Africa AIDS is as much a heterosexual disease as a homosexual one. The sexual promiscuity of homosexual communities in the Western world and the historical accident that their members were the first from the West to contract the disease from its African source may be sufficient to account for the predominantly homosexual character of the Western epidemic. The second reason to be sceptical of the verdict about homosexuality commonly reached lies in the difficulty found even by defenders of a traditional sexual ethic in showing that homosexual sex is of its nature depersonalising. It is notable that Roger Scruton in his recent lengthy defence of traditional sexual values can find no absolutely convincing demonstration of this point, only hints of an argument that cannot be developed further.<sup>9</sup> Homosexual sex is a departure from the Western norm and it may have vicious forms, but whether it is inherently vicious is open to argument from *within* the conservative standpoint. Reference to Biblical pronouncements, or to a narrow teleology of the sexual organs might settle this issue straight away, but we have questioned how convincing these arguments are already.

Mention of homosexuality and AIDS confirms the general message that needs to be drawn from a treatment of AIDS and sexual morality. The AIDS epidemic can validly be used to reopen debates on issues in social morality. It can and should make us think afresh about fundamental values. But it should not be used to provide instant confirmation of our prejudices.

#### Notes and references

- 1 The medical facts about AIDS and its spread and treatment in this paper are taken from Dr C Farthing, Public Lecturer on AIDS at King's College London, February 1987 and from V G Daniels, AIDS: the acquired immune deficiency syndrome (second edition). Lancaster, MTP Press, 1987.
- 2 The form and content of my treatment of these issues reflects the discussion at an interdisciplinary seminar on AIDS at the Centre of Medical Law and Ethics held at King's College on 5 February

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1987. The parties present at the seminar are not, however, responsible for my presentation of the issues here.

- 3 This section is a shortened version of a paper which appeared in the autumn 1987 issue of *Religion Today*. The material is reused by kind permission of the editor.
- 4 R F Atkinson. *Sexual morality*. London, Hutchinson, 1965, page 45.
- 5 J Harris. *The value of life*. London, Routledge and Kegan Paul, 1985, page 138.
- 6 See Sir Immanuel Jacobovitz. *Jewish medical ethics*. New York, Bloch, 1975, pages 4-5.
- 7 For this application see L Paul. *Coming to terms with sex*. London, Collins, 1969; and R Scruton. *Sexual desire*. London, Weidenfield and Nicholson, 1986.
- 8 See 1 above (Daniels), page 50.
- 9 See 7 above (Scruton), page 310.

## REVIEW OF THE YEAR

### 2. JUDGES, HUMAN RIGHTS AND THE SOURCES OF MEDICAL LAW

Simon Lee

#### Introduction

Two issues underlying medical law deserve to be highlighted in a review of 1987. First, the need is now becoming urgent for medical law to break free from its reliance on tort, family and criminal law and to base itself squarely on a firm foundation of human rights law. Second, there is a need to clarify the respective roles of legislators, judges and other decision makers in developing medical law.

I have chosen four cases from 1987 to illustrate these points. The first concerned abortion<sup>1</sup> and led to much misguided criticism of the wrong people. The second<sup>2</sup> was the question of authorising the sterilisation of a mentally handicapped teenager. The third<sup>3</sup> explored the question of a patient suing a doctor for lack of informed consent. Both these cases led to much justified criticism of the right people. The fourth<sup>4</sup> involved the decision to deny *in vitro* fertilisation to a former brothel-keeper. This led to surprisingly little criticism or comment, whether guided or misguided. After considering these four court-based instances of medical law in action, I will conclude by showing how there are some signs of optimism that a fourth issue, AIDS, is being considered by the right people in the right way, with due respect for human rights.

On the way to that conclusion we will spend some time in analysing the four cases. Since medical law is of deep concern to so many non-lawyers, it seems to me especially important that the role of judges be understood. Otherwise, there is a

danger of the medical profession, moral philosophers and others who follow the courts' involvement in this area criticising the wrong targets in the wrong way. In particular, judges are often criticised for Parliament's failings.

Lawyers disagree on how judges do and should decide hard cases. My view is that there are three elements to their decisions. First comes their interpretation of the past law – the statutes, precedents and principles which bear on the dispute before them. The second factor is the judges' evaluation of the consequences of their decision. The third consideration is the judges' view of their own role in our democracy. In particular, judges must have some perception of when it is their role to override the first factor in the light of their estimation of the second factor. Some judges will dare to replace the old law with what they consider to be a more desirable rule. Others will feel that they should be careful not to usurp the role of Parliament in this regard. The 'right' answer to the judicial role must vary according to what other institutions in the democracy are, or are not, doing, on what the area of law is, on what the level of the judge is, and on what is the disparity between the first two factors. Too many critiques of the judges by lawyers assume that only the first consideration is significant. Too many critiques of judges by pressure groups, including the medical profession, assume that only the second factor is relevant.

Turning away from judges to the second theme of my review of the year, too many non-lawyers assume that arguments about human rights are only a matter of well-intentioned theory. But this ignores the growing body of human rights *law*. In a completely different, non-medical, context, 1987 should have brought home to the British public that lawyers referred to human rights law in deciding such issues as the (non-)publication of *Spycatcher*. The argument in the House of Lords revolved around Article 10 (guaranteeing freedom of expression, subject to exceptions) of the European Convention on Human Rights, to which the UK is a signatory. In the medical sphere, other Articles of that document are relevant. Medics and philosophers must take on board not only the texts of human rights norms but also the associated jurisprudence of international and domestic courts in interpreting these provisions. My insistence on the significance of human rights law

should not be read as a critique of John Eekelaar's call for more attention to be placed on moral duties. I agree that 'the concept of legal rights is a social construct'. Indeed, I have argued that position at length in a paper published in a collection of which John Eekelaar was the co-editor.<sup>5</sup> In many ways, I wish that the growing body of international human rights law was called human duties law. But it isn't and the point here is that, regardless of how we would judge the moral arguments about duties, our country is already committed to legal norms which are themselves a resolution of moral dilemmas. Under the UK's constitution, international agreements are not automatically enforceable in our courts but our government is committed to introducing changes to bring our law into line with the rulings of, say, the European Court of Human Rights. As *Spycatcher* showed in a non-medical context, the judges are likely to shortcircuit that process and apply the human rights law for themselves.

### Abortion

In our first case, *C v S*, a student sought to stop his former girlfriend from aborting their child. The fetus was of about 20 weeks gestation. The argument turned on the interpretation of a phrase in a 1929 statute. The father lost. The judges' analysis of the statutory phrase 'capable of being born alive' was dismissed as 'astonishing', 'confused' and a 'mockery' by some pro-life groups. This reaction is code for saying that those pro-lifers would have twisted the law to suit their moral convictions if they had been the judges. But that is one of the reasons why they are not judges. Judges should not subvert the law. However much I believe in human rights and moral duties, that does not imply that I expect judges to smuggle their or my views into the law at the expense of Parliament's resolution of the moral conflict. The lesson which I see in *C v S* is not that the judges failed to appreciate the human rights dimension of a medical law dispute but that *Parliament* needs to reconsider abortion from that perspective. As I write, Parliament is at last proposing to do just that. Until it does resolve the matter, we should not criticise the judges when our real quarrel is not even with the statute which they were honestly and plausibly interpreting but with another statute, the Abortion Act 1967.

Indeed, those who accuse the judges of incompetence or malevolence would do better to consider the context of the Infant Life (Preservation) Act 1929. In 1928, Mr Justice Talbot's direction to a Liverpool jury was that 'It is a felony to procure abortion and it is murder to take the life of a child when it is fully born, but to take the life of a child while it is being born and before it is fully born is no offence whatever.' The following week Lord Darling introduced a Bill to plug this gap between abortion and murder, to protect in his words children 'in the course of being born'. Although those words were changed in Select Committee to 'capable of being born alive', Lord Darling emphasised in moving the Second Reading that 'It really is a Bill designed to prevent children being destroyed at birth'. The long title of the subsequent Act talks of the 'destruction of children at or before birth' and the offence is termed 'child destruction'.

As this legislative history suggests, it is not surprising that the Abortion Act 1967 s5(1) was passed on the assumption that the 1929 Act would protect viable (and only viable) fetuses. Section 5(1) of the Abortion Act states that 'Nothing in this Act shall affect the provisions of the Infant Life (Preservation) Act 1929 (protecting the life of the viable foetus)' – the parenthesised phrase is in the original. Section 1(2) of the Infant Life (Preservation) Act 1929 states: 'For the purposes of this Act, evidence that a woman had at any material time been pregnant for a period of twenty-eight weeks or more shall be *prima facie* proof that she was at that time pregnant of a child capable of being born alive.' This implies that the purpose of the Act was to protect the lives of viable fetuses and so it gives a clue as to what the phrase in section 1(1) means. All this is merely to observe that the father's action was a long shot. The Act was not designed for his problem, which was a quarrel with the lax Abortion Act 1967.

Now what about the actual words, 'capable of being born alive'? Well, they could in everyday language be taken to cover a fetus from day one. Or they could be taken to mean only a viable fetus. But the legal techniques for interpreting such an ambiguous phrase require the judges to look at the Act as a whole, to construe the words in their context, with a sense of the purpose for which the Act was passed. I have endeavoured

to do this and to show why it was wishful thinking for anti-abortionists to expect the courts to interpret 'capable of being born alive' as covering the fetus in question.

The judges unanimously chose breathing as the test and said that the affidavit evidence suggested that a fetus at this stage of development would not be able to breathe naturally or even with the aid of a respirator, because the lungs would be too immature. It follows that when the fetus is able to pass that test, say by 24 weeks, the offence of child destruction would be committed. So the presumption of 28 weeks, contained in s1(2) of the Infant Life (Preservation) Act 1929 is not the last word and the true legal limit for abortions is 24 weeks or whenever the fetus is capable of breathing.

The Pavlovian reaction of criticising the judges should therefore be resisted. Indeed, both counsel for the mother and for the father concluded their arguments by praising the judges for the manner in which they handled the case. The litigation went through the High Court, Court of Appeal and on to the Appeal Committee of the House of Lords in record time. Mrs Justice Heilbron and the Court of Appeal were so certain and convincing that the Appeal Committee of the House of Lords saw no possibility of success in a full hearing.

Once the Appellate Committee had decided not to hear full argument, the Court of Appeal thereafter declined to give further details of their reasons. Counsel for the father protested vigorously but made no impression on the Master of the Rolls. This has the disadvantage that we are left without the detailed account of the factors which the judges say influenced them. But there is little doubt in the minds of those who were in court (as I was) that beneath the analysis of the statutory language, lay the concern of Sir John Donaldson and his brethren that they should not upset the controversial border between legal and illegal abortions. They sensed the consequences of a change in the assumptions as to the law and they felt that any changes should be made by Parliament. In my terminology, therefore, the judges' vision of their own role and their vision of the consequences of the alternative decision probably influenced their account of what the past law decreed. Nevertheless, their interpretation of the past

law was itself convincing, although anyone can see that this was by no means the only or even perhaps the most obvious interpretation.

### Sterilising the mentally handicapped

Within a matter of weeks, however, another issue of law and morals did pass that last hurdle and the Law Lords gave leave for the Official Solicitor to appeal against a decision of the Court of Appeal to authorise the sterilisation of a mentally handicapped 17-year-old girl. Whereas the abortion case turned on the interpretation of statutes, the sterilisation decision allowed the judges more or less complete discretion. In this latter case, therefore, the Law Lords considered a disturbing question: should a court authorise the sterilisation of a mentally handicapped young woman?

Some parents, doctors and social workers might believe that they themselves should be able to decide whether or not to sterilise a mentally handicapped teenager who is under their care. But the Court of Appeal and the House of Lords in *Re B* have both rightly rejected that view. To that extent, their judgments are to be welcomed as a tightening of the law and practice. Yet all the judges who heard this case at all levels were prepared to authorise the sterilisation of this particular 17-year-old. They said that they were acting in 'the best interests of the girl' as a matter of last resort.

At this point, several objections could be made. First, some critics believe that the compulsory sterilisation of those unable to give or refuse consent is always unacceptable. Second, some believe that sterilisation should only have been contemplated for therapeutic or medical reasons, and not merely as a form of contraception. Third, some would accept other forms of contraception but believe that the irreversible nature of sterilisation makes it the wrong choice. Fourth, some accept the need for sterilisation in some such cases but fear a drift down the path towards eugenics (a link which the judges strenuously denied) and bemoan the insensitive, demeaning discussion which lumps together people under labels such as 'the mentally handicapped'. Fifth, some critics regret the Law Lords' failure to specify the criteria implicit in their vague 'best

interests' test and wish that their Lordships had examined the human rights at stake in greater detail. Sixth, some critics feel that the judges missed an opportunity to clarify the law's responsibilities towards the mentally handicapped in adult life, since the ruling was based on a statutory jurisdiction which ends at the age of 18. Seventh, some critics think that the real blame lies at Parliament's doors where legislators consistently duck sensitive moral dilemmas and leave the judges to resolve the ensuing mess. Finally, some people are disturbed by the facts of the particular case and in particular by the fact that the girl in question was sterilised only days before her eighteenth birthday, at which point the authority of this judgment would expire. Professor Ian Kennedy and I raised many of these concerns in an article in *The Times* on the day before the Law Lords' hearing. That article<sup>5</sup> was discussed in the course of counsel's argument but in the end judges rejected any alternatives to the approach of the lower courts.

In contrast to the wide range of public concern, the Law Lords themselves had no doubts at all about their decision to authorise the sterilisation. Lord Bridge, for example, claimed that 'It is clear beyond argument that for her pregnancy would be an unmitigated disaster. The only question is how she may best be protected against it. The evidence proves overwhelmingly that the right answer is by a simple operation for occlusion of the fallopian tubes ... I find it difficult to understand how anybody examining the facts humanely, compassionately and objectively could reach any other conclusion.'

But one might perhaps reach other conclusions for a variety of humane, compassionate and objective reasons. First, would pregnancy really be such a disaster? Second, if it would be disastrous, should she not be protected against sexual exploitation so that the question of pregnancy would never arise? Third, even if one was prepared to tolerate a contraceptive solution to her problems, is irreversible sterilisation the right option?

On the first claim that pregnancy would be a disaster, Lord Oliver, for instance, says that 'Should she become pregnant, it would be desirable that the pregnancy should be terminated'. But why? The baby would not be at risk. The mother according to the specialist evidence, 'would tolerate the

condition of pregnancy without undue distress'. Admittedly, she would have to be delivered by Caesarean section since she would panic unduly during normal childbirth. The Law Lords were worried that she would pick at the post-operative scar but that hardly seems a ground for an abortion, even within the present legislation.

On the second question of sexual experience, none of their Lordships takes the point that she ought to be protected against sexual exploitation whether or not she could become pregnant. They seem to be contrasting the fear of an unsterilised girl becoming pregnant causing her to lead a restricted life with the greater freedom that they would allow her once sterilised. Are these really the alternatives?

On the third point of choosing between various contraceptive measures, there is an argument that the irreversibility of sterilisation makes it even less desirable and even more symbolically degrading. On the other hand, the Law Lords thought that, say, the contraceptive pill would involve a daily violation of the girl's privacy and would be far more risky as a contraceptive and would perhaps have harmful side-effects for a girl with her particular physical problems (such as epilepsy and obesity). That takes us back to the point that everybody in the case seems to have assumed that *some* form of contraception was inevitable and desirable.

What is most surprising, given the gravity of the issue and the widespread public concern, is that the judges seemed to gloss all the difficult questions in their judgments. Their analysis of the past legal principle, the future consequences of their decision and their ability to have decided differently was unsatisfactory. But were there any signs of hope in the case? Yes. The public outcry at least forced the Law Lords to consider the matter and if the pressure is maintained, this might in turn lead on to our legislators considering a proper structure of rights and care for mentally handicapped people of whatever age and whatever mix of abilities and disabilities.

What is particularly intriguing for students of medical law and judicial reasoning, however, is that another final court of appeal, the Canadian Supreme Court, had just examined the same question. In the case of *Re Eve*, it answered the same question with the opposite conclusion.

The Canadian Court had three advantages over the Law Lords. First, it had time. It took five years for Eve's case to move from the provincial court to the Supreme Court. It took 16 months after the hearing for the Supreme Court to produce its judgment. Here the Court of Appeal reached its decision on 23 March. The Law Lords decided after only one day's argument on 2 April and gave their judgments three weeks later. The rush was because everyone in the British case assumed, perhaps wrongly, that if the girl were not sterilised before her 18th birthday on 20 May, nobody, not even the court, would thereafter have been able to authorise treatment for her since statute decrees that she will then cease to be a ward of court.

The second advantage was that there were several *amici curiae*, presenting the views of interested third parties to the Canadian court so that it could benefit from the widest range of arguments.

The third helpful factor was that the Supreme Court was able to rely on the research of the Canadian Law Commission. The Law Commissions here, however, have consistently failed to address questions of medical law and ethics. Parliament fails to reform the law to keep pace with medical developments and the challenges they pose. The courts meanwhile are left to solve issues of the greatest moral import, often in a rush and without the benefit of considered reflection of public policy. This has happened with teenage contraception and with abortion, it is happening with surrogacy and it may well happen with AIDS. The time for a better method is overdue. The long-term solution must be to follow the US, the French and others by creating a Commission on Medical Law and Ethics.

La Forest J, giving judgment for all nine members of the Supreme Court in *Re Eve*, concluded that 'The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantage that can result from it, have persuaded me that it can never safely be determined that such a procedure is for the benefit of that person. Accordingly, the procedure should never be authorized for non-therapeutic purposes under the *parens patriae* jurisdiction.'

The Court agreed that sterilisation may, on occasion, be

necessary and lawful as 'treatment of a serious malady'. The crucial distinction is between sterilisation for medical reasons (therapeutic sterilisation) which may be permissible and sterilisation for non-medical reasons such as for contraception, which was absolutely unacceptable to the Supreme Court.

If the Law Lords were moved to disagree with the Supreme Court's careful, well-researched and long-planned judgment, there should perhaps have been time for more than one day's pause and reflection.

The Canadian Supreme Court said that wardship is but a statutory example of a general common law principle that the state will take care of those who cannot take care of themselves, known as the *parens patriae* jurisdiction. Lord Eldon's emphatic assertion in an 1827 decision should have been followed by the Law Lords: 'it belongs to the King as *parens patriae*, having the care of those who are not able to take care of themselves, and is founded on the obvious necessity that the law should place somewhere the care of individuals who cannot take care of themselves, particularly in cases where it is clear that some care should be thrown round them.' Clearly, to Lord Eldon this jurisdiction is not limited to the care of children under 18. If the House of Lords had followed Lord Eldon and the Canadian Supreme Court, the urgency would have disappeared. The case could then have been adjourned for more measured examination of the question of sterilisation.

Four possible approaches could have been adopted.

The first would have been to defer to the girl's mother, guardians and doctors. Some claim that this has been the practice in this country. But Heilbron J rightly rejected that argument in a case decided ten years ago. The question is not one of solely clinical judgment since it involves issues of human rights which transcend the competence of doctors.

The second approach was better, and the one which in effect the Law Lords adopted; but it was still unsatisfactory. This is the 'last resort' test adopted by the Court of Appeal. This has the advantages of removing the decision to a disinterested authority, the court, and of emphasising that sterilisation is only to be considered *in extremis*. But 'last resort' needs defining, otherwise it could slip back into the first approach of what doctors deem to be the last resort.

The third method would have been that of the Canadian provincial court in *Re Eve*. The 'best interests' and 'last resort' tests are spelt out in detail. Sterilisation would only be available if a series of 14 difficult steps are taken. The onus is very firmly on those who are arguing for sterilisation to show that it is the only solution to a real problem. They must show, for instance, that the real object of the operation is to protect the girl not her parents or other carers; that other forms of contraception would be unworkable; that there is a real danger, rather than a mere chance, of pregnancy; and that there is more compelling evidence than the mere existence of a handicap that pregnancy would have a damaging effect. At first glance, this is the most attractive path to take as a compromise solution.

But the fourth and preferable approach would have been that of the Supreme Court. Even if all the provincial court's 14 hurdles could be surmounted, the Canadian Supreme Court would still not permit sterilisation because, as Lord Eldon said, under the *parens patriae* jurisdiction 'it has always been the principle of this Court, not to risk damage to children which it cannot repair'. The irreversible nature of sterilisation means that although the 14 steps might lead a court towards, say, long-term contraceptive injections for a mentally handicapped girl, they could never justify the final step of sterilisation, a step which could never be retraced.

Why did the Law Lords opt for the second option? They were unimpressed by the argument that there is a fundamental right to procreate which no law can interfere with except where medically necessary for the sake of the girl's present health. This argument does not assert that each woman has a right to bear children. That would fly in the face of reality. It asserts only that the state through its law may not deprive a woman of the opportunity of procreating. As the Canadian Law Commission observed, 'sterilized mentally retarded persons tend to perceive sterilization as a symbol of reduced or degraded status. Their attempts to pass for normal were hindered by negative self perceptions and resulted in withdrawal and isolation.'

To some this is an absolute right. To others it could be overridden if the state could show good reasons. But what reasons could be good enough? Similarly if we focus on

another basic human right, the right to bodily integrity and freedom from interference, some would speak in absolutes while others would argue for exceptions. But again, what could count as a good reason for an exception?

The only good reason for an exception to either right is if the operation is needed for the health of the girl. For this to be valid, it must be limited to existing conditions of ill health requiring treatment. Admittedly, some prophylactic measures may be justified, for instance vaccination against a future threat. But absent such a limited case, irreversible surgery performed for prophylactic purposes which are hypothetical and could perhaps be avoided by other means cannot qualify under the heading of therapeutic sterilisation. Yet the Law Lords rejected this approach, finding the distinction between therapeutic and non-therapeutic elusive or unhelpful.

Sterilisation does not of course absolve those with responsibility for the girl from using their best endeavours to protect her from sexual exploitation. And we can still argue for the general principle against sterilisation. The Supreme Court would reject exceptions beyond the therapeutic proviso by saying no, find another way, do not use irreversible surgery to solve social problems, the danger to human rights is too great.

There is a broader danger for human rights if Parliament continues to abdicate its responsibilities. As the Supreme court itself acknowledged in *Eve's* case: 'Judges are generally ill-informed about many of the factors relevant to a wise decision in this area. They generally know little of mental illness, of techniques of contraception or their efficacy. And, however well presented a case may be, it can only partially inform. If sterilization of the mentally incompetent is to be adopted as desirable for general social purposes, the legislature is the appropriate body to do so. It is in a position to inform itself and it is attuned to the feelings of the public in making policy in this sensitive area.' This is a statement of brutal honesty which deserves our attention when we consider the role of judges as law-makers. There are limits to their competence and legitimacy.

Hence the wider significance of the *Re B* argument was that public attention will be drawn to yet another problem of medical law and ethics where Parliament had failed to guide the judges. In future, Parliament should take on these dilemmas of

modern medicine. And as a first step, it should set up an appropriate body to review the problems and put the arguments before the nation. Although our judges deploy their considerable concern and ability when confronted by these questions under adverse conditions, the present British piecemeal approach to such fundamental problems is inadequate. Issues of human rights deserve more than their day in court.

The sterilisation case again raises a couple of wider issues of relevance to lawyers. The first is a question of legal procedure: why do we have a two tier system of appeals? What is the role of the Law Lords? We do not really need two sets of appellate judges to rehearse the facts. Yet that is more or less all they did in *Re B*. The Law Lords declined to take the opportunity to decide the *parens patriae* point: whether there is an inherent jurisdiction to care for those who cannot care for themselves which survives the age limit of 18 which terminates the statutory wardship jurisdiction. They declined the opportunity to give more guidance than is provided by simply incanting the phrase 'best interests'. Not only does this case therefore raise questions about the role of the full Judicial Committee, it also reminds us of the role of the Appeal Committee of the House of Lords which in 1987 grew accustomed to convening at great speed to decide whether to grant leave in cases of great public interest. The Law Lords' willingness to consider the granting of leave in such circumstances is to be applauded. But observers may be unsure of the criteria by which they decide when to grant and when to refuse leave. In *C v S* (the abortion case discussed above), the Committee refused leave to appeal. In *Re B*, however, leave was granted. Since the Law Lords in the sterilisation judgment clearly did not find any difficulty at all in resolving the point of law, it might seem that it was the public clamour which weighed heavily with the Appeal Committee, and perhaps the cumulative clamour building on dissatisfaction in some quarters with both Court of Appeal decisions. It seems that the law Lords were really taking the opportunity to explain the facts which they felt justified the Court of Appeal decision which had been subjected to so much criticism. The Law Lords' judgments in *Re B* gave the impression that the general principle enunciated by the courts below was blindingly obvious and that the outcome turned

on the facts. Yet they wanted very much to restate the Court of Appeal's judgment authoritatively in the face of public criticism. How this squares with the role of the second tier appeal deserves deeper examination.

The second point of legal practice which arises from the Law Lords' hearing is of more specific concern to medical law and human rights, namely the unsatisfactory treatment accorded to the European Convention on Human Rights in the course of oral argument. The Law Lords seemed happy enough to be referred to the Convention. But they were not referred to the relevant Articles, and the interpretation of the Article which was cited left something to be desired. Counsel for the Official Solicitor, representing the child's interests did not refer to the Convention, nor did counsel for the mother. But counsel for the local authority mentioned Article 12 in order to rebut the argument that the girl in question had a right to procreate. Article 12 is not the most conspicuous success story within the Convention. It runs as follows: 'Men and women of marriageable age have the right to marry and to found a family, subject to the national laws governing the exercise of this right.' That may not say much but it perhaps says more than counsel supposed. She argued that since the girl in this case did not have the capacity to consent to marriage she did not come within the terms of the Article and thus did not qualify for the right to found a family. Others might suppose that the European Convention would not be interpreted by its own institutions so as to allow the right to procreate only to married couples. And they would suspect that there must be more relevant Articles elsewhere in the Convention. They would be right. Article 8 on the right to respect for one's private and family life, Article 3 prohibiting inhuman or degrading treatment and even Article 2's right to life ought to have been considered. Even if the appropriate rights had been pinpointed, some idea of the jurisprudence and interpretive approach of the European Court of Human Rights should surely have been forthcoming. Of course, counsel and the court were arguing at short notice but if the Law Lords really are determining questions of law of general public importance, the principles of human rights law deserve more careful attention.

### A reversible decision on informed consent to sterilisation

Our third case involved a Mrs Gold who underwent a sterilisation which was unsuccessful. She subsequently gave birth to another child and brought an action for damages for negligence against the Haringey Health Authority, alleging, *inter alia*, that it had been negligent in not warning her of the risk of failure. She was successful at first instance and was awarded £19,000 damages. The health authority successfully appealed to the Court of Appeal.

The Court of Appeal in *Gold v Haringey Health Authority* was apparently taken through the judgments in *Sidaway v Bethlem Royal Hospital Governors* [1985] 2 WLR 480 'speech by speech, and paragraph by paragraph' (per Lloyd L J at p 894). Nevertheless, the Court focused on the most restrictive interpretation of the requirements of informed consent, relying on the speech by Lord Diplock in *Sidaway*, whereas the speech by Lord Scarman was much more expansive and would surely have helped Mrs Gold. Indeed, Lord Scarman's *Sidaway* opinion is the *locus classicus* for an appreciation of the interconnection between human rights and medical law. I have praised Lord Scarman's speech on other occasions<sup>7</sup> so this time I shall simply contend that the other opinions in *Sidaway* would also have helped Mrs Gold and that the Court of Appeal's approach in *Gold* therefore represents a distorted view of *Sidaway*. Lloyd L J's conclusion in *Gold* was that *Sidaway* required the application of the *Bolam* test, that is, a doctor 'is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art ... merely because there is a body of opinion that takes a contrary view.' In *Gold*, all the medical expert witnesses said that they would have warned Mrs Gold of the risk of failure but that a sizeable proportion of doctors, up to 50 per cent according to one, would not have done so in 1979 when she had the operation. Accordingly, the Court of Appeal felt that the Health Authority were excused under the *Bolam* test as endorsed by Lord Diplock in *Sidaway*, since a responsible body of practitioners would not have mentioned the risk.

As in *Sidaway*, there was some doubt about what the patient

was told and what she asked about but we do know that she was told that the operation was irreversible. If she had asked about the risk of failure, *all* the *Sidaway* judgments, including Lord Diplock's, would have assumed that she should have been told the true facts unless there were exceptional therapeutic reasons for misleading her. But even on the hypothesis that she did not ask, and even if we ignore Lord Scarman's magisterial affirmation of the rights of patients to know (which to my mind trumps Lord Diplock's restrictive account of the law), the other judgments in *Sidaway* should have been explored by the Court of Appeal in *Gold*.

Lord Bridge, for example, with whom Lord Keith of Kinkel concurred, endorsed the words of Laskin C J in the Canadian case of *Reibl v Hughes* (114) DLR (3d) 1, 13 cited at [1985] 2 WLR 480, 504, in averring that he was not prepared 'to hand over to the medical profession the entire question of the scope of the duty of disclosure, including the question whether there has been a breach of that duty'. His Lordship added the observation (at 505) that 'the judge might in certain circumstances come to the conclusion that disclosure of a risk was so obviously necessary to an informed choice on the part of the patient that no reasonably prudent medical man would fail to make it'. His Lordship insisted that, if there were a conflict between medical practitioners on proper practice, 'the judge will have to resolve that conflict'. He was even prepared to intervene against a practice as endorsed by all the expert witnesses if necessary. This is very close to Lord Scarman's position that the court must decide whether 'it is satisfied that a reasonable person in the patient's position would be likely to attach significance to the risk'.

Lord Templeman did not once mention the *Bolam* test. He too emphasised that 'where the practice of the medical profession was divided... it will be for the court to determine' the standard of disclosure expected of doctors. He too was not prepared to defer to the medical profession in all cases. He insisted that 'the doctor impliedly contracts to provide information which is adequate so as to enable the patient to reach a balanced judgment' and the court would intervene if the doctor failed to do so, or as he put it, if the doctor 'blundered'.

So the Court of Appeal's decision ignores the main thrust of the judgments in *Sidaway*. *Sidaway* should not be treated as Informed Consent (Lord Scarman) 1: Uninformed Consent (the rest of their Lordships) 4. There is plenty of material in the speeches of Lord Brandon, with whom Lord Keith agreed, and Lord Templeman to incline a subsequent court towards the view favoured by Lord Scarman than the other extreme favoured by Lord Diplock. In concentrating on Lord Diplock's judgment to the exclusion of the others, the Court of Appeal has surely erred and threatened to stop the admirable development of a coherent doctrine of consent.

#### Decommissioning commissioning couples

In our fourth case, *R v St Mary's Hospital, ex p Harriott*, a woman who wished to have a child but who was infertile applied to be considered for *in vitro* fertilisation under the National Health Service. She was refused treatment and she challenged her rejection in court. Mr Justice Schiemann decided against her but his judgment opens up several questions of interest to medical law and ethics. As the judge said: 'This I believe is the first occasion when a decision to refuse treatment for an illness, and for the present purposes infertility may be regarded as an illness, has been the subject of an application for judicial review.' He declined to decide the questions of principle as to whether an ethics committee or a consultant could be subject to judicial review. In the case before him, the judge was convinced that even if review was available in principle, it should not be exercised in practice because the committee and the doctor had not erred in law.

But ethics committees which came to absurd decisions might well find the courts intervening:

'If the committee had advised, for instance, that the IVF unit should in principle refuse all such treatment to anyone who was a Jew or coloured then I think the courts might well grant a declaration that such a policy was illegal.'

Similarly, the judge was prepared for the purpose of the argument to assume that the doctor-patient relationship was within his purview. He also could 'see arguable grounds for

criticism of [the consultant's] decision in December 1984 not to treat the applicant (because the patient had not been given a chance to argue that her case was exceptional, and because she was misled as to the true reasons for refusal) but the patient had had a later opportunity to argue her case and now knew the real reasons'.

Those were, incidentally, that the patient's applications to foster or adopt children had been turned down by the social services department, that she had criminal convictions for running a brothel and soliciting for prostitution, and that her husband's children by a former liaison were in care.

Two questions arising from this case intrigue me. First, should judges be involved in second-guessing decisions to refuse treatment for an illness? This relates to our concern about who should decide issues in our society. Considerable interest surrounded a similar question a couple of years ago when an area health authority decided to discontinue kidney dialysis treatment for a Mr Sage, although that controversy did not reach the courts. The recent trend in judicial review had been to expand the potential powers of the courts, for example in relation to the Takeover Panel which is not a statutory body but which has been held to be amenable to judicial review as if it were a public body. In that spirit, there seems little doubt that administrative decisions within the health service will be subject to review. These undoubtedly are decisions made by 'public' bodies. But how do we distinguish administrative and clinical decisions? Well, the judges are not going to be taking the decisions for doctors, they are merely concerned to see that the doctors have acted fairly and not unreasonably in determining who gets what treatment. If there are limited places available within a hospital for *in vitro* fertilisation or kidney dialysis, I would expect the courts to intervene if bias were shown by doctors, or if they decided without listening to the arguments of the people adversely affected. The same applies if an ethics committee purports to decide such matters, although it is likely to escape judicial attention if it merely offers informal advice to those who decide.

Second, were the reasons in this case appropriate? Did they reflect the human rights law which lurks in the background? What about Article 12 of the European Convention, for

example, which guarantees that 'Everyone has the right to marry and to found a family subject to the national laws governing the exercise of this right'? Does this Article mean that everyone has the right to found a family except those who are infertile and who used to run brothels? When Parliament comes to legislate on the Warnock proposals, it ought to face the question of eligibility for treatment which Warnock raises. One factor to bear in mind is that sooner or later someone who is refused treatment will be 'taking their case to Europe'.

## AIDS

Let me conclude with the briefest mention of the law's response to AIDS.<sup>8</sup> Again, I could look at cases, such as the decision to restrain a newspaper from publishing the names of doctors who were continuing to practise despite having AIDS.<sup>9</sup> But this time, I wish to direct attention to a fact that is obvious to all those who do not suffer the academic lawyer's crippling disease of appellate court-itis, in which the royal courts of justice become the centre of the universe. That is to say, what happens in the courts is by no means the most important element of the battle against AIDS. The more important decision makers have been, and will be, doctors, the government and individuals who are at risk of contracting AIDS. I was delighted to see that the government responded to the threat of AIDS not by seeking to change laws but by seeking to change attitudes through an advertising campaign. We might argue about the advertising tactics but the idea of fighting a modern problem with a modern solution is surely right.

As for the doctors, they seemed in disarray. The BMA, for example, saw a split between the leadership and the members as to the rights of doctors to know whether their patients are AIDS victims and therefore whether blood could be tested without a patient's consent. The BMA Council triumphed ultimately by showing that a leading criminal barrister endorsed their view and that of the the DHSS, that taking blood without consent could amount to assault.

The tables were turned later in the year when a newspaper was prevented by a judge from naming doctors who have

AIDS. The rights of AIDS victims were perhaps more clearly brought home to doctors by this episode. But, as I have said, I do not want at this stage to dwell on the courts again. I merely raise the problems posed by AIDS to demonstrate the two themes of this paper. First, we must be careful not to infringe human rights law in our eagerness to react to a medical dilemma. Second, we need to think carefully about the proper division of roles within society in resolving medical dilemmas: what are the proper spheres of not only the courts, but also Parliament, the government and, I would stress, the medical profession itself? AIDS will lead to some litigation but countering AIDS is primarily the responsibility of individual citizens, their doctors and their government. It requires massive resources, energy, skill and commitment rather than changes in the law.

The law is not a panacea for all society's ills. We should not rush to change the law, still less should we rush to court when medical problems arise. But the law does have a limited role to play. In particular, we can expect our judges increasingly to apply human rights law when there is a danger that solutions to medical problems might infringe the rights of an individual.

#### Notes and references

- 1 *C v S* [1987] 1 All ER 1230.
- 2 *Re B* [1987] 2 All ER 206.
- 3 *Gold v Haringey* [1987] 2 All ER 888.
- 4 *R v St Mary's Hospital, ex p Harriott*, New Law Journal, 6 November 1987.
- 5 S Lee. Towards a jurisprudence of consent. In: J Eekelaar and Bell (eds). *Oxford essays in jurisprudence (third series)*. Oxford, Oxford University Press, 1987.
- 6 I M Kennedy and S Lee. The rush to judgement. *The Times*, 1 April 1987. I have borrowed freely from our article in this section.
- 7 S Lee. *Law and morals*. Oxford, Oxford University Press, 1986; and see 5 above.
- 8 S Lee. AIDS, law and morals. In: Cosstick. *AIDS: meeting the community challenge*. St Paul Publications, 1987.
- 9 *X v Y*, *The Times*, 7 November 1987.

## DOES A MOTHER HAVE LEGAL DUTIES TO HER UNBORN CHILD?

John Eekelaar

In attempting to sketch an approach towards answering this question, I have reluctantly been taken into deeper waters than I would care to enter. I will need to reopen the argument about abortion (how could it be otherwise?); I shall glance at the question of embryo experiments; and I shall have to consider the relationship between law and morals.

The complexity of the issues can be glimpsed by considering the following sequence of propositions, all of which either represent the law, or proposals for law reform, somewhere:

- a. Within a mild regime of regulation, English law allows doctors, with the mother's consent, to destroy her fetus at least before it is presumed to be capable of sustaining independent life.<sup>1</sup>
- b. The Committee of Inquiry into Human Fertilisation and Embryology (Warnock committee)<sup>2</sup> recommended that experiments on human embryos should be permitted for a period of fourteen days from fertilisation. At the end of that time, but not later, the embryo should presumably be destroyed unless it could be transferred to a woman.
- c. In California<sup>3</sup>, a criminal charge has been brought against a woman who suffered from *placenta praevia* and whose child was born dead after (it was alleged) she took amphetamines, had sexual intercourse with her husband in disregard of express medical advice, and had failed to summon medical help (as she was told she should) immediately bleeding began.

d. In many jurisdictions<sup>4</sup>, and under the old common law, a child could bring proceedings with respect to injuries inflicted on it before its birth by the negligence of the defendant. However, in England since 1976 it can do this only if the defendant would be 'liable in tort' to the mother; furthermore, the child can bring no action against its mother for antenatal injuries, unless her negligent act was committed while driving.<sup>5</sup> On the other hand, a mother's neglect, or abuse of her unborn child can rightly be taken into account in deciding whether, immediately after its birth, the child's health or development are being avoidably impaired or neglected, with the consequence that the child might be removed from its mother.<sup>6</sup>

Can these differing positions be accommodated within a coherent framework of morality and a defensible view of the relationship of law to morality? Perhaps they merely reflect compromises between fundamentally irreconcilable moral positions. After all, if the point of departure assumes a fetus can have rights, it becomes very difficult to see why these warrant protection at 30 and not, say, 20 weeks gestation, or why an embryo of four weeks demands protection which is not afforded to one of ten days. Similarly, if it is assumed that there is total unity of identity of mother and fetus, such that a mother can no more owe moral duties to her fetus than she can towards her kidneys, it is hard to explain any limitation at all on abortion or the vesting of any cause of action in a child for events occurring before its birth. It may also be difficult to understand why there should be any restriction on embryo experiments, for if the mother is free to act towards the embryo within her as she pleases, it is not clear how the fact that another embryo has developed externally to the mother confers on it a moral status *vis-a-vis* third parties which the internal embryo lacks.

Of course it is true that individuals are to be found who hold one or other of those irreconcilable opinions, and it may be that our morality, and the law, is torn between the two, and that any intermediate position must be incoherent. But might there be a third way which can stand upon principles independent of those claimed by the opposing factions? I am not here claiming that it is possible, with sufficient 'Herculean'

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reflection, to ascertain a deep morality within our society which can accommodate both positions and which can, at least in principle, be reached through a 'proper' appreciation of the present law.<sup>7</sup> But there may be areas of agreement in situations which are sufficiently proximate to these that they can provide the basis of an approach which 'fits' reasonably closely to accepted values. I would not argue that this would provide the 'right' answer to the question posed in the title of this essay; but it could be helpful in clarifying the basis which might underlie our legal and moral approach to it.

If the mother, or anyone else, is to owe a duty towards an unborn person, then it would be a logical implication that the fetus has a right to the performance of the duty. I have referred earlier to the claim that such duties exist which is predicated on the assertion that a fetus does, indeed, have 'rights'. I observed that, if that were true, it would be difficult to defend distinctions based on various stages of embryonic development. This is simply because, while there may indeed be significant *physiological* differences between various stages of cellular and fetal development, I am not convinced that any of them are sufficient to carry the extreme *moral weight* which permits, for example, destruction at one moment and requires protection at the next. One reason for thinking this is that there are so many developmental stages which are, in various ways, crucial: fertilisation, implantation, initial cell division, formation of the 'primitive streak', origination of the central nervous system, beginnings of functional and sensory activity, capability of independently sustaining cardiac or brain activity, or breathing. Put another way, no single stage of embryonic evolution, after its commencement at fertilisation, seems in itself capable of generating a moral conclusion.<sup>8</sup> This view runs counter to that maintained by many writers, but the *practical consequences* of their views can be supported, at least to a large extent, by the different set of arguments presented below. For the present, however, I feel compelled to adopt the position that, if a fetus has rights, it has them always; if it has not, I am not convinced how or at what point they are acquired.

For similar reasons, we should resist attempts to solve the moral issue by recourse to definition in forms such as the

assertion that a fetus acquires rights (or is owed duties) when it becomes a 'person', or attains the condition of a 'human being'. Definitions are descriptions of factual phenomena; their applicability in the present context is, as a matter of language, uncertain. They cannot in themselves resolve the moral issues of how people should behave.<sup>9</sup> Nor, it seems, can they easily settle legal issues, such as the 'right' of the unborn to institutional protection.<sup>10</sup>

There is another reason why an attempt to find a solution on the basis of assumptions about fetal rights may be misplaced. When I examined the evolution of the idea of children's rights<sup>11</sup>, I concluded that the concept of legal rights was a social construct which follows, and does not precede, the imposition of legal duties on others. Furthermore, for the idea that X has a right truly to be established, it must be socially accepted that the duty imposed on others towards X is owed for X's sake alone and is not merely contingent on other interests. An analogous view could be maintained with respect to moral rights. Indeed, in his classic exchange with Judith Jarvis Thomson<sup>12</sup>, John Finnis took a similar view in the context of moral argument. The rhetoric of rights obscured the true underlying moral issue, which was: what behaviour was morally permissible towards another human being?

Rather than determining what a woman's duties should be on the basis of whether or not a fetus has rights, it might be more fruitful to inquire what duties social morality requires of the mother (and others) towards the unborn. This, it may be said, is no easy matter; it is the very point in issue. This is true. But by focusing on the mother, not the fetus, it becomes possible to relate the choices before her and their effects on her to analogous situations and in this way to construct a coherent moral framework.

The most closely analogous situation is that of any parent of a child who is born alive. Here social morality, and the law, expect parents to make decisions which will frequently relegate their own interests beneath those of their children. Parents are expected to love their children. Even if they do not, they will be expected to make significant modifications to their mode of life and pursuit of their own self-interest in order to provide adequate care for their children. Serious transgressions may

result in state intervention and the removal of the children<sup>13</sup> and sometimes the prosecution of parents.

It may be asked how the analogy may be drawn between the moral perception of duties towards born children and towards the unborn. I would prefer to put the question the other way. In what way are the distinctions between the situations sufficient to generate plausible differences in moral evaluations of behaviour? It will be evident that I am not considering the fact of being unborn as *in itself* sufficient to justify such distinctions. For, just as I have indicated that I do not consider the various stages of fetal development as being sufficient in themselves to establish moral categories, it does not seem to me that the passage of the child from the uterus is in itself an event which holds crucial implications regarding the morality of behaviour towards the child. From the point of view of the *object* of the moral behaviour, then, I can make no distinction between the born child and its unborn counterpart, at any stage of development.

But those observations notwithstanding, the situation prior to birth raises issues which are of great significance in constructing a moral view of a person's behaviour towards the unborn. The most obvious is that the mother is unable, without violating the fetus, to escape the 'relationship' between herself and the unborn, a point of significance to which I will return. In contrast, it may be said, a parent may transfer his or her obligations towards a living child to another. But the situation is not quite so simple. Indeed, under English law, 'a person cannot surrender or transfer to another any parental right or duty he has as respects a child'.<sup>14</sup> What this means is that any agreement attempting to achieve such a transfer will be ineffective to divest the parent of his or her responsibilities. If this is to be done, it must be within a supervised context, within some statutory regime, such as adoption or child care law. It is true, however, that informally a parent may arrange for another to take over the care of his or her child, something which is obviously not open regarding the unborn. But it is not so easy to divest oneself of legal responsibility.

The question, as far as the present point is concerned, is to draw attention to both the similarities and the differences

between the total<sup>15</sup> inability of a mother to surrender the care of her unborn child and the related, much circumscribed, freedom of the mother of a born child to do so and to consider how they affect the moral content of her behaviour towards the child. I shall not consider this point further at this stage but move to the next, closely related, comparison. This is to note that by carrying a child a woman will usually, unless there is external intervention, reach the stage of childbirth, bringing with it certain risks to the mother's well-being which may be calculated on a general statistical basis or, indeed, estimated in an individual case. As far as a born child is concerned, while the demands of child care may take their toll, a child does not make anything approaching the same physical demands. However, a child might become subject to a physical condition which can be alleviated only by the parent undergoing medical intervention (whether it be blood transfusion or organ or tissue transplant). It is unlikely that assistance by the parent could be compelled by law. But morality may well expect the parent to help, unless the procedure were life threatening to the parent. A parent who risks, or sacrifices, his or her life for a child is regarded as a moral hero(ine), going well beyond what 'ordinary' morality would expect.

To disapprove of abortion (I am confining myself at present to the moral background, so I do not speak of legally disallowing) amounts in effect to prescribing social and physical activity on the mother. This point was at the centre of Thomson's analysis of the morality of abortion<sup>16</sup>, in which she maintained that it was unsound to base a moral position on the expectation that individuals might, or should, undertake activities which mere 'decency' suggested should be done to help others. This, she claimed, was the character of the 'moral' obligation that allegedly fell upon women when it was argued that they owed a duty towards their unborn children. She expressly rejected the analogy with parenthood, where parents are generally accepted as having a moral duty actively to assist their children on the ground that parents *assume* such responsibility to the children in a way which a pregnant woman does not towards her fetus. But, to a family lawyer, this is to mistake the basis of parental responsibility. This rests not upon conscious commitments 'undertaken' by the parents, but the

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simple fact of dependency. The financial liability of an unmarried father, perhaps of all fathers, is a straightforward example.<sup>17</sup> Indeed, anyone who finds himself in care of a young child, whether sought or not, owes at least some duties towards it.<sup>18</sup>

The analogy, therefore, holds. The differences arise with respect to the degree of self-denial which it is morally defensible to expect of a pregnant woman when compared to a mother of a born child. Parents are not expected to place themselves in life-threatening situations for their children; nor, perhaps, to be placed at serious risk of psychological disturbance. We can surely say the same for the mother-to-be. But, it will easily be observed, the immediate parallel is limited. We may not expect parents to risk really serious harm on account of their children, but nor do we think they can kill them to avoid that harm. At most, a parent may be morally excused (although not applauded) if he allows his child to die rather than to submit to gravely life-threatening procedures. Unless one discovers a morally relevant distinction between 'allowing' a child to die in such circumstances and 'directly' aborting a fetus, the analogy would only permit abortion if the alternative were a serious threat to the mother's life. So, what then if continuing to carry and give birth to the child would not risk the mother's life but would subject her to conditions (such as serious psychological damage) which a parent of a born child would not be called upon to endure? Here it seems to me the physical inseparability of mother and fetus determines the issue. Killing of the born child is ruled out because it represents one particular social choice among others; to permit it would weaken the resolve to find alternative solutions to the parents' difficulties. But for the unborn there are no such alternatives. Only by abortion can the mother be protected from undergoing conditions a parent would not be expected to tolerate. Nature, not social ordering, has made it so. Although to allow abortion in such circumstances would never be acceptable to those who hold that it is always wrong so to assault innocent life<sup>19</sup>, to do so is morally neither incoherent nor implausible. But there must be commensurability between the act and the conditions threatening the mother. Only severe and long-term harm, resulting from the continued pregnancy and birth of the

child (*not* simply from having to care for it after birth) would provide sufficient moral justification.

It must be some such reasoning that underlies much abortion legislation like that which applies in England. Abortion may be legally performed if a doctor believes that this is immediately necessary to save the mother's life or prevent grave permanent injury to her physical or mental health, or if two medical practitioners certify that the continuance of the pregnancy would involve a risk to the life of the woman, or injury to her physical or mental health, or any existing children, greater than if the pregnancy were terminated.<sup>20</sup> However, it is equally clear that the wording of the Act is much wider than the moral principle stated earlier, for it permits termination essentially on the ground simply that the birth of the child would cause some 'injury' to the mother's physical or mental health which would not have happened had the child not been born. The types of 'injury' contemplated seem to include injuries ('worry', 'anxiety', 'financial hardship') of a lesser kind than those which I earlier argued might morally justify abortion, and indeed cover many which parents are expected in any case to endure.

But to slip from argument in the purely moral domain to considering the wording of a statute should not be permitted without the interposition of a further stage of argument. Twenty-five years ago, H L A Hart put forward the concept of 'critical morality' to deal with the question 'whether the enforcement of morality is morally justified'. It is premised on the assumption that 'the use of legal coercion by any society calls for justification as something *prima facie* objectionable to be tolerated only for the sake of some countervailing good'.<sup>21</sup> Some justification (that is, in critical morality) must therefore be found if state coercion is to be used to enforce a moral position. The mere assertion that the prohibited act 'is immoral' provides no such justification.

Whatever moral position is eventually taken about abortion, the issue of critical morality will be crucial. The overwhelming reason for this lies in the fact that unlike the discharge of a parent's duties towards living children (which are capable of supervision – though this can be difficult) and ultimate enforcement, a woman has unique control over her own body.

Prohibition of abortion by the criminal law has been proved to be notoriously ineffective and, indeed, productive of great evil. In this sense the relative flexibility of the English abortion legislation may be defended. The social, and indeed, personal costs of holding women who are insistent on abortion to a moral framework to which they do not necessarily subscribe are unacceptable to any reasonable form of critical morality. It will be utterly futile in situations if forms of post-coital 'contraceptive' become available 'over the counter'.

The famous decision of the United States Supreme Court in *Roe v Wade*<sup>22</sup> ought to be considered as a decision on 'critical morality' in this sense, rather than the 'positive' morality of abortion as such. The issue had, of course, to be determined within the framework of US constitutional law. The Court's conclusions were that: states could not override the woman's own decision within the first trimester of pregnancy as this would violate the woman's privacy interest; that states might intervene if they so chose during the second trimester on the basis of their interests in the women's health; and that they might regulate or proscribe abortion during the final trimester on the basis that, when the fetus becomes 'viable', the state acquires an interest in protecting fetal life. These conclusions can be represented as an attempt to formulate a critical morality of abortion on a principled basis. On the analysis adopted here, the free scope afforded to the woman and her medical advisers in the first trimester can be seen to respond to the acute difficulties of legally controlling a woman's options during that period, whatever view is taken of the morality of abortion as such. The solution of the problem during the second trimester is left to individual states, but only so far as this is necessary to protect the mother's health. The attitude to the final trimester can be regarded as permitting the legal enforcement of a positive morality expressive of the view that the fetus acquires overriding 'rights' at that stage but not before.<sup>23</sup> This view would be inconsistent with the position taken here, that an unborn child cannot sensibly be regarded as acquiring some kind of moral personality at some essentially arbitrarily chosen point in development. But it could be defended on a different basis. Provided the mother can reasonably be expected, on moral grounds analogous to those

which apply to parents of born children, to bring the pregnancy to term, legal enforcement of this position at this late stage in pregnancy is both realistic and not unduly oppressive in itself. When a mother has carried the child for six months, legal control over her behaviour towards it would not necessarily violate a defensible critical morality.

Of course the issue need not be approached solely in terms of the applicability or non-applicability of the criminal law. Health and social policies have the capability of encouraging, discouraging or merely regulating the practice of abortion.<sup>24</sup> On these matters I need say nothing. I have probably said too much on abortion in any event. My purpose was to place the discussion of a mother's duties towards her unborn child within a framework which was strong enough to extend to the totality of issues related to the morality of antenatal parenting. I will return to some others later. But it is an essential step in any claim that a mother may owe duties towards her unborn child. It might have been possible to avoid the abortion issue by arguing that, even if a mother is under some obligation towards the unborn child, this is conditional on the child's live birth. It is like saying that a person has no duty to accept a child (for example, by adoption) but, if he does, the duty arises. Only in some such way can the existence of 'right' to abortion be reconciled with the San Diego case mentioned earlier.

That position is unsatisfactory, however, for these reasons. First, a mother's decision to continue a pregnancy may not be as consciously clear-cut as the principle seems to require. A woman who muddles indecisively through a pregnancy and is later prosecuted for criminal neglect of the fetus may feel justifiably aggrieved if her sister, who had an abortion, is absolved. Second, under most present laws, a fetus will be protected against abortion at some stage before its birth. The 'right' to reject the child is then lost. I have already explained that I consider the division of pregnancies into stages for such purposes unconvincing. Abortion cannot therefore be so easily set aside from the general question of duties towards the unborn.

So we may now turn to that general question; and, consistently with the framework I have attempted to construct, I shall argue

that it is morally permissible to draw upon the duties which parents have towards their born children in formulating duties owed to the unborn. The Children and Young Persons Act 1969 encapsulates the duties to living children well in the expression that the child's health must not be avoidably impaired and its development must not be avoidably prevented. The *Review of Child Care Law* phrased it differently: there should not be 'a substantial deficit in the standard of health, development or well-being which can reasonably be expected for the child' and this should not result from the child 'not receiving or being unlikely to receive the care that a reasonable parent can be expected to provide'.<sup>25</sup> The government White Paper substantially accepted this suggestion. There should be no evidence of harm or likely harm to the child and this should not be attributable to the absence of a reasonable standard of parental care.<sup>26</sup> The significant addition made by the child care review and the White Paper is that it needs to be shown that the child's condition is brought about by a failure in parental care. This was in any case the practical position under the 1969 Act, where decisions were in fact made on the 'reasonableness' of the parenting which the child received. The issue does indeed go to the reasonableness of parental behaviour. (Not, as in the White Paper's formulation, the reasonableness of the 'standard'. The standard may be low, even unreasonably so, but if the causes do not relate to parental unreasonableness, there is no basis to intervene.) There seems to be no reason in principle why such duties should not be owed towards an unborn child. We need to look at the current law to discover if, indeed, they are.

### Criminal law

We need not spend long with the criminal law. Section 1(1) of the Infant Life Preservation Act 1929 provides that it is an offence if any person, with intent to destroy the life of a child capable of being born alive, by any wilful act causes the child to die before it has existence independent of its mother. The way the Court of Appeal struggled with the concept of capability of being born alive in *C v S*<sup>27</sup> illustrates how unsatisfactory any such concept must be from the point of view of the positive

morality of abortion. It is hard to see the moral relevance of whether or not the child, if then delivered, would be able to breathe, or the relevance of the current state of medical technology, which has pushed further and further back the time at which a child delivered prematurely has a chance of living. Within the American context, concern has been expressed that the receding date of 'viability' (at which time abortion may be disallowed) is narrowing the scope of the 'woman's right to choose', and has led to the suggestion that viability should be assessed without taking into account the applicability of artificial aid.<sup>28</sup> But all babies depend on external ministrations of some kind to survive; on what principle are some modes excluded? Another suggestion has been that viability should be fixed at the 'earliest point at which there has been verified fetal survival'.<sup>29</sup> It is impossible to feel comfortable with moral evaluations which are conditional on such considerations.

But arbitrary divisions may not be unreasonable when the pragmatic questions of legal control are an issue. At some point it does become practicable, and neither oppressive nor counter-productive, to prohibit legally the destruction of the unborn child. It would not, in this view, be unreasonable, and indeed might hold positive advantages, to select a specific date after conception when abortion becomes illegal unless justified by moral principle. The introduction of criminality would then become relatively certain, and pretence that it reflected a moral position could be abandoned.

For completeness, it should be added that it is possible that grossly negligent procedures which result in the child's death after birth may amount to manslaughter.<sup>30</sup>

#### Child care law

The issue of parental duties towards the unborn was not specifically before the House of Lords in *D v Berkshire CC*.<sup>31</sup> The House held that the expression 'is being' in relation to impairment of health or prevention of development in section 1 of the Children and Young Persons Act 1969 denoted a continuous state of affairs which stretched from before birth into the future. Lord Goff stated that he wished to avoid a

construction 'which produces the result that any child born suffering from the symptoms or effects of some avoidable antenatal affliction could be described, after its birth, as being a child whose proper development is being avoidably prevented or whose health is being avoidably impaired. The mere fact of a past avoidable prevention of proper development or impairment to health is not, in my opinion, sufficient to fulfil the condition, even if there are symptoms or effects which persist or manifest themselves later.'<sup>32</sup> In this view, evidence of antenatal behaviour is relevant only as part of a picture of the child's actual and prospective situation after it is born, immediately before the proceedings in question were initiated.

Since the current law requires a court to be satisfied that the prescribed circumstances exist at the relevant time (which is when coercive action is first sought, and this can happen only after the child is born), such a conclusion seems to be inevitable. But should it continue to be so? Under the proposals of the *Review of Child Care Law* and the White Paper, two limbs of the three-part test are satisfied if the child suffers a sufficient deficit in health or development and if this is attributable to lack of reasonable parental care. There seems no reason why these conditions should not be satisfied in the situation which Lord Goff wished to avoid. For a drug-damaged child may well be in this condition as a result of failing to receive the care which a reasonable pregnant women can be expected to provide; at least, if the expression 'parent' in both documents is interpreted as including pregnant mothers. This, however, is unlikely unless expressly enacted. But even if it were so enacted, the third limb of the requirements for intervention would need to be satisfied, namely, that the order proposed for the child was the most effective means of safeguarding the child's welfare. If there was no reason to doubt the mother's present parenting abilities, it is unlikely that any order would be necessary. On the other hand, situations might occur where an order of some kind (for example, supervision) might be thought desirable to safeguard the child's welfare in the case of a child who had been damaged through (say) the mother's drug abuse during pregnancy even if the mother was now able to provide reasonable parenting. It might, for example, be useful as a basis for monitoring the

mother's continued rehabilitation. If it were thought that that would be a realistic and useful power, it might be advisable to ensure that the expression 'parent' in the new legislation does extend to parents-to-be, thus overcoming the limited scope of the present law as stated by Lord Goff.

### Tort law

Section 1 of the Congenital Disabilities (Civil Liability) Act 1976 imposes liability for injuries incurred by a child who is subsequently born alive if the injuries were incurred as a result of 'an occurrence' during the mother's pregnancy or labour and if the defendant would be 'liable in tort' to the mother for that occurrence. This means that the mother may reduce her unborn child's eventual claim either by agreement or through her own responsibility for the occurrence; for example, if she had freely consented to the administration of a dangerous drug. Nor can the child, when born, sue the mother. These provisions were a departure from the earlier common law, under which persons could be under a duty of care to the child itself, and would be liable to an action by the child for breach of the duty.<sup>33</sup> An exception is permitted if the unborn child was injured by the mother's negligence while driving, an overt ploy to get at the mother's insurers.

Fetal injuries caused by a third party will usually be the result of an occurrence for which the tortfeasor will also be liable to the mother; if nothing else, the damage to the child is likely to cause the mother emotional shock, for which the tortfeasor will be liable. But it seems undeniable that the real gist of any such action lies in a duty towards the unborn person; that the 1976 Act has made it parasitic on the commission of a tort to the mother seems to be an unwarranted technicality which will be of little practical effect. But more worrying is the fact that the child's claim may be reduced, or even barred, by the mother's own actions. The Law Commission advocated this, not because it considered that a mother had no duties towards her child, but because third parties, it felt, should be able to control the extent of their liability when dealing with an adult. A possible 'hidden' duty towards an unknown fetus could, the Commission thought,

deter people from dealing with women, particularly pregnant women.<sup>34</sup> There seems to be some basis in this, for a parent, for example, can enter into an agreement with a carrier which restricts the latter's liability towards the parent's child. If this is so, it should be no different for the unborn child (though in either case the extent of restriction permitted may be limited by the Unfair Contract Terms Act 1977). But a distinction can surely be drawn between this situation and one where a third party's negligence (recklessness, even deliberate assault) towards the unborn child is compounded by the mother's contributory behaviour. Rather than permitting reduction in the third party's liability, it would be sounder, and more just, to treat both adults as joint tortfeasors towards the child.

It seems equally dubious to disallow a claim between child and the mother. The Law Commission was persuaded by memoranda from the Bar Council and the President of the Family Division that such litigation would be 'unseemly', raise family tensions, and risk abuse by an unscrupulous spouse on family breakdown.<sup>35</sup> These lawyer-like arguments are supported by no evidence and, oddly, did not result in barring actions against the father.<sup>36</sup> If it is 'unseemly' to permit this type of claim, so it also must be unseemly to allow actions between children and their parents for negligent behaviour towards them after their birth; perhaps negligent care in the home or outside it. But that would be thought to be a very poor reason for barring a claim. However, it must be confessed that the issue is not of much practical importance. The reason is that children simply do not sue their parents for such things.<sup>37</sup> Even in obvious cases of deliberate child abuse, who has heard of the child bringing civil action for compensation against the responsible parent? First, there is no machinery to which they have access to make such a course a realistic possibility; second, there are no additional resources which any such action could reach which are not available to the family in any case (insurance cover for such eventualities being virtually unknown). So the situation is that unless responsibility for the injury can be attributed to a source outside the family (the manufacturer, or seller, of a defective product; or the negligence of some professional) the child goes uncompensated. (In some cases a child may be entitled to compensation under the

Criminal Injuries Compensation scheme; but this avenue has so far been little explored.)

The position of the unborn is much the same. Even if they were given the right to sue the mother for antenatal injury, such actions would be as rare and pointless as actions such by children for injuries caused to them after their birth. But this, as I have argued above, is no reason to create a statutory prohibition upon them. Even less is it a reason to allow a third person (perhaps a drug manufacturer), who would be worth suing, to take advantage of defences which may be open to them if sued by the mother. My conclusion as to tort law, therefore, is that this restriction on a child's rights of action against third parties should be removed and that the right of action by a child for injuries caused to it by its mother before its birth should be restored. However, it should also be recognised that this second change would in itself be of negligible importance so far as the general question of compensating children for conditions arising antenatally is concerned. That demands a totally different approach to compensation, outside the tort system.

#### A new form of supervision or control?

Under the present child care law, intervention is possible in cases of child neglect only after the child has been born. The changes proposed by the *Review of Child Care Law* and the White Paper do not contemplate any alteration to this principle (although I have argued above that, when intervention does take place, there is a case for allowing it on the basis of the failure of the mother to act reasonably towards her unborn child during pregnancy). But is there a further case to be made for permitting intervention at an earlier stage? If, after all, a child's right to sue its mother for careless management during her pregnancy were to be restored (as I have suggested) then, it might be said, some authority should be empowered to take action on the child's behalf before the harm is inflicted or becomes worse. It would not be difficult to find the appropriate legal test: if a mother needs to behave as a reasonable mother after the child is born, surely she can be expected to behave as a reasonable prospective mother during her pregnancy. There is,

however, one overwhelming reason why such a course cannot be pursued. Even assuming (and it is a large assumption) that agreement could be reached on the many borderline areas of controversy about what is correct behaviour during pregnancy, or that only cases where very clear and likely harm to the child would be in issue, what mechanisms of enforcement are open? There are none that I can think of which would be remotely acceptable within our libertarian traditions. The theories shatter against much the same rocks as those which prevent the full legal enforcement of the morality of abortion which I outlined earlier. But that does not of itself destroy the idea that there may indeed be duties, akin to those of a reasonable parent, owed by the reasonable parent-to-be. But their implementation may lie in the fields of education, inducements and incentives.

#### Tailpiece on embryo experiments

Although this essay has been centrally concerned with a mother's duties towards her unborn child, it has proved impossible to view that question in isolation from the broader ethical context in which it arises: what duties does anyone owe to the unborn? The essence of the argument has been that, in moral principle, the unborn should be viewed in the same way as the born, though the call which the biological relationship makes on the mother has considerable relevance to determining the moral evaluation of the mother's behaviour towards the unborn. In addition, however, whatever the conclusion of moral argument, the unique control which the mother has over her body drastically limits the extent to which such a conclusion may be translated into law.

But these limitations on moral principle do not apply when it is a question of the behaviour of third parties towards the embryo. There is no sense in which their actions are constrained in any morally relevant sense by their relationship to the fetus; nor does enforcement pose particular problems. If it can be accepted that the various stages of embryonic development do not in themselves have moral relevance, then the conclusion can only be that behaviour towards an embryonic fetus should be governed by the same legal principles as behaviour towards a born child.

Notes and references

- 1 Parliament. Abortion Act, 1967, s 1; *C v S*, The Times, 24, 25 February 1987.
- 2 Department of Health and Social Security. Report of the Committee of Inquiry into Human Fertilisation and Embryology. Cmnd 9314 (Chairman: Dame Mary Warnock) London, HMSO, 1984, paragraph 11.22.
- 3 Newsweek, 1 December 1986, page 54.
- 4 For the United States see L Glantz. Is the fetus a person? A lawyer's view. In: W B Bondeson, H T Engelhardt, S F Spicker and D H Winship (eds). *Abortion and the status of the fetus*. Dordrecht, D Reidel, 1983, pages 107-117.
- 5 Parliament. Congenital Disabilities (Civil Liability) Act 1976, ss 1-2.
- 6 *D (a minor) v Berkshire County Council* [1987] 1 All ER 20.
- 7 The reference is to the opinion espoused by Ronald Dworkin and propounded in various places and forms, most recently in Law's empire. London, Fontana, 1986.
- 8 The issue of viability will be explored further below: see text associated with notes 27-29. On this view, the argument in *C v S* (see 1 above) as to whether the fetus of 21 weeks was capable of being born alive, although of legal significance, was of no *moral* importance.
- 9 See Harry A Nielsen. Toward a Socratic view of abortion. *American Journal of Jurisprudence*, 18, 1973, pages 105-113. Striking examples of approaching the issue through definition by a court and in legal criticism are found in H Patrick Glenn. The constitutional validity of abortion legislation: a comparative note. *McGill Law Journal*, 21, 1975, pages 673-684 (discussing a decision of the German Constitutional Court) and Robert M Byrne. An American tragedy: the Supreme Court on abortion. *Fordham Law Review*, 41, pages 807-862.
- 10 The fact that six courts of highest jurisdiction in the West have decided differently on the right of the unborn child to legislative or constitutional protection illustrates the fluctuating and supremely subjective nature of the juridical person subject to protection: M T Meulders-Klein. The right over one's body: its scope and limits in comparative law. *Boston College Law Review*, 6, 29,

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1983, at page 61, citing decisions of US, Austrian, German, French, Italian and Canadian courts.

- 11 John Eekelaar. The emergence of children's rights. *Oxford Journal of Legal Studies*, 1986, pages 161–182.
- 12 John Finnis. The rights and wrongs of abortion: a reply to Judith Thomson. *Philosophy and Public Affairs*, 1973, pages 117–145; reprinted in R M Dworkin (ed). *The philosophy of law*. Oxford, Oxford University Press, 1977, chapter 7.
- 13 R W J Dingwall, J Eekelaar and T Murray. *The protection of children*. Oxford, Basil Blackwell, 1983.
- 14 Parliament. *Children Act 1975*, s 85(2).
- 15 In cases of 'total' surrogacy, a woman's fertilised ovum may be implanted in a surrogate. But this is possible only in limited circumstances. Were it possible for a fetus to be transferred easily to a surrogate at any time during pregnancy, the parallel between pregnancy and child-raising would be even closer and would surely affect moral perceptions of behaviour towards the unborn.
- 16 Judith Jarvis Thomson. A defence of abortion. *Philosophy and Public Affairs*, 1971, pages 47–66; reprinted in R G Dworkin (ed). *The philosophy of law*. Oxford, Oxford University Press, 1977, chapter 6.
- 17 See also the basis upon which a step-parent acquires responsibility over a 'child of the family', where the requirement is 'treatment' not 'acceptance': see Stephen M Cretney. *Principles of family law*. London, Sweet and Maxwell, 1984, pages 377–378.
- 18 See *Children Act 1975*, s 87(1): 'A person has actual custody of a child if he has actual possession of his person' and (2) 'While a person not having legal custody of a child has actual custody of the child, he has the like duties in relation to the child as a custodian would have by virtue of his legal custody'.
- 19 See 12 above.
- 20 Parliament. *Abortion Act 1967*, s 1.
- 21 H L A Hart. *Law, liberty and morality*. Oxford, Oxford University Press, 1963, pages 17 and 20.
- 22 *Roe v Wade* 93 SC 703 (1973); see the recent application in *Margaret S v Treen* 597 F Supp 636 ED La 1984, noted in *Journal of Family Law*, 24, 73, 1985–6.

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- 23 See Renee C Fox. Ethical and existential developments in contemporaneous American medicine: their implications for culture and society. In: John B McKinlay (ed). *Law and ethics in health care*. Cambridge, Mass, The MIT Press, 1982, at page 357.
- 24 Richard Wasserman. Implications of the abortion decisions: post Doe and Roe litigation and legislation. *Columbia Law Review*, 74, 1974, pages 237-68. The American literature discusses these issues extensively.
- 25 Department of Health and Social Security. *Review of child care law*. London, HMSO, 1985, paragraph 15.25.
- 26 Department of Health and Social Security and others. *The law of child care and family services*. Cmnd 62. London, HMSO, 1987.
- 27 See 1 above.
- 28 Leslie Ann Cohen. Fetal liability and individual autonomy in resolving medical and legal standards for abortion. *UCLA Law Review*, 27, 1980, pages 1340-1364.
- 29 Patricia A King. The juridical status of the fetus: proposal for legal protection of the unborn. *Michigan Law Review*, 77, 1979, pages 1647-1687.
- 30 *R v Senior* 1(1832) 1 Moo CC 346.
- 31 See 6 above.
- 32 See 6 above, pages 43-44.
- 33 *Whitehouse v Jordan* [1981] 1 WLR 246; see J M Eekelaar and R W J Dingwall. Some legal issues in obstetric practice. *Journal of Social Welfare Law*, 1984, pages 258-270.
- 34 Law Commission. Report on injuries to unborn children. Law Commission No 60. London, HMSO, 1974, paragraphs 67-71.
- 35 See 34 above, paragraph 58.
- 36 On this point, and for a general discussion of the 1976 Act, see P J Pace. Civil liability for pre-natal injuries. *Modern Law Review*, 40, 1977, pages 141-158.
- 37 Donald Harris and others. Compensation and support for illness and injury. Oxford, Oxford University Press, 1984, pages 62-64 show that less than 10 per cent of victims of accidents other than road accidents or accidents at work (that is, 'home and leisure'

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accidents) even *contemplate* claiming damages, and that only 7 per cent of *all* accident victims aged under 15 think of doing so. Clearly, where a 'home or leisure' accident occurs to a child, the chances of a claim being considered are quite minimal.

## AIDS: Law, Liberty and Public Health

Roy Porter and Dorothy Porter

From the Hippocratic Oath to the present day, attention in medical ethics has focused on the moral ties – rights, duties, obligations – between doctor and patient. But there is a public dimension as well to the dilemmas posed by the threat of disease and the counterbalancing powers of medicine. We have been all too ready to ignore these wider moral problems over the last generation, comfortingly assuming that they boil down to technical issues or practical matters of money (high demand, scarce resources), or cynically assuming they are just ‘party politics’.

The AIDS epidemic has once again reminded us of the urgent reality of the moral choices facing medical decision-making.<sup>1</sup> But AIDS has caught too many people unprepared. Many people, from the scaremongering tabloids to well-meaning professors<sup>2</sup>, have urged policies and programmes for dealing with the epidemic, with (it seems) little capacity to form subtle and responsible evaluations of the moral and political implications of their recommendations.<sup>3</sup>

Part of the problem is that much of the public discussion has taken place in a historical and philosophical vacuum. In the heat of debate, it is easy to treat the dilemmas raised by AIDS as if they were something new, as if doctors and governments had never before been faced with agonising problems of having to act to prevent or regulate lethal epidemics. Nothing could be further from the truth.<sup>4</sup> Throughout the nineteenth century, the high levels of morbidity and mortality of a newly industrialised society led to the rise of what was variously called sanitary science, public hygiene, preventive medicine and state medicine.<sup>5</sup> This necessarily created new powers, and

so required acute public debate as to the scope and limits and the legitimacy of those powers in the regulation of public health. There were no simple solutions; no clear consensus immediately formed. Dissent, pressure groups, controversy, policy reversals and compromise formed the order of the day. Medical, metaphysical, legal, moral and religious arguments all fought for mastery, and the outcome – one which endowed the administrative state with considerable powers while falling well short of the general policing, let alone the criminalisation of disease – often, we might conclude, smacked more of pragmatism than of philosophy. Amid all the sound and fury of competing ideologies, the subtle art of the administratively possible was central to the politics of health. Nevertheless, our predecessors debated, with both logic and passion, the essential questions of the status of individual liberties in the face of the threat which a diseased individual poses to society, the issue of the balance of self and society. We can do worse than to refamiliarise ourselves with the language and dilemmas of these medico-political issues by re-examining how the Victorians and their successors grappled with the ethical problems posed by epidemics, by sexually transmitted diseases, and by the rise of public health.

Our aim in this paper is thus to survey a number of major initiatives chiefly in the fields of infectious and sexually transmitted diseases in England over the last century and a half. It will concentrate attention on what has been a long-running debate as to the relations between state powers and individual liberties, the public health and individual medical care (as classically defined in the one-to-one confidential contractual relationship between patient and doctor). These legislative and administrative milestones have been well surveyed by historians of the administrative state or the welfare state. But the philosophical, ethical and jurisprudential issues they raise have largely been ignored. We are not ethical philosophers, and our aim in this chapter is not to hammer out an ethical or political policy with regard to AIDS and the public health. Rather it is to place before the reader some of the historical materials valuable for forming such judgments.

Victorian values – if by that we mean self-reliance and a strident individualism – existed long before the Victorians.

One of the earliest comprehensive philosophical vindications of the fundamental rights of the individual against the state is set out in William Godwin's extremely influential *Political Justice* (1793).<sup>6</sup> Godwin believed that existing governments improperly usurped the rightful liberty of the individual in many departments of life; the fundamental freedoms of speech, of publication, of assembly, of religion, of moral autonomy and action were all unjustly impeded by traditional authority. Yet there is one conspicuous absence in Godwin's indictment of the state. He makes no complaint about the state interfering with the health or the medical liberties of the individual. The silence is not an omission. It merely reflects the realities of late eighteenth century England. Though there was a state religion, there was no state medicine. In this England differed from many parts of the Continent. Indeed, the very phrase 'medical police', so common in Continental enlightened absolutism as a part of *Kameralwissenschaft*, and familiar even in Scotland, was hardly even an Anglicised expression.<sup>7</sup>

Some two thirds of a century later, John Stuart Mill's *On Liberty* (1859) constitutes the classic mid-Victorian philosophical defence of the freedom of the individual.<sup>8</sup> Fighting what he deprecated as the tyranny of mass opinion, which he feared was fast turning itself into a new *legislative* tyranny, Mill argued for the priority of the individual over the stifling claims of state and society. The state was nothing but a collection of individuals. The fundamental purpose of the state should be to protect natural personal liberties, rather than, as in Burke's organic and conservative political philosophy, to enforce political, religious and moral allegiance and orthodoxy within a superorganic whole. Mill brought to bear arguments partly metaphysical (individuals had the fundamental right to dispose of their lives as they pleased), and partly utilitarian (self-reliance built character, intellectual dissent stimulated the march of mind, and in the long run these benefited both individual and society at large). The only ground for curbing one man's liberty, he argued, was when its exercise substantially and materially infringed the free exercise of another's.<sup>9</sup>

Mill gave his case for liberty a flourish by making pious appeals to the martyrs of history – Socrates, Galileo, and so on – and presenting telling illustrations from everyday life.

Suicide should be decriminalised, because in the last resort it was the individual not the society who was proprietor of his life. Similarly, poisons should be freely offered for sale, as should narcotics and alcohol. Society had the right to educate, and to warn, but not to prohibit indulgence in such vices. The danger of their abuse was less than the stifling evils of paternalism.

Mill is, however, strangely silent on matters of public health. He believed that bad morals and bad belief systems should be permitted, because they would be destroyed by free and fair competition and truth would prevail. But did the same apply to bad air, bad drinking water, or to contagious diseases? To what extent and under what circumstances was the enforcement of public health legitimate? Mill does not say. It cannot be claimed that it is anachronistic of us to put this question to Mill. For the powers of the state to enforce the public health had been controversially transformed beyond recognition during his own lifetime. Above all, the General Board of Health, set up by the Public Health Act of 1848, had been granted unprecedented powers to regulate the physical environment relating to health – in such matters as pestilential sewers and contaminated water supplies – powers which its secretary Edwin Chadwick exploited up to the hilt.<sup>10</sup> This Board, and the sanitary reforming ethos of Chadwick, proved unpopular and short-lived. It was succeeded in 1858 by a new Medical Department at the Privy Council where Sir John Simon, as the Medical Officer, instituted a period of state medicine in Victorian Britain.<sup>11</sup> Furthermore, the Medical Act of 1848 had empowered local authorities to establish medical officers of health, who were mandated to monitor morbidity, coordinate the provision of public health services in a locality and who possessed legal powers of removal under a series of Nuisance Acts passed in the 1850s and 1860s.<sup>12</sup> And most radically of all, legislation of 1853 made universal childhood smallpox vaccination compulsory, carrying fines and even imprisonment for defaulters.<sup>13</sup>

Horrified by this tide of administrative centralisation, *The Times* had taken its stand in 1848 in defence of the sacred cow of *laissez faire*, blustering that it would rather take its chance with cholera than be bullied into health.<sup>14</sup> But this Canute-like

gesture had proved futile. The current of compulsory public health, backed with state sanctions, was flowing powerfully. In the 1860s, the Contagious Diseases Acts (1864, 1866, 1869) empowered (under specific circumstances) the medical inspection of women believed to be common prostitutes. If found diseased, they could be compulsorily detained and treated.<sup>15</sup> Somewhat later, the whole domain of infectious diseases came under surveillance and administrative regulation. The Notification of Infectious Diseases Acts enabled, from 1889, and required from 1899 onwards, that any incidence of a listed disease (smallpox, diphtheria, scarlatina, croup, typhus, and so on) be compulsorily reported to the medical officer of health by the medical attendant or head of household. Subsequently the patient could then be removed to an isolation or fever hospital until cured and their families quarantined at home.<sup>16</sup>

Looking back as early as 1868, less than a decade after Mill's *On Liberty*, Sir John Simon could wax eloquent about the dramatic benefits of enlarging the domain of public health regulation:<sup>17</sup>

It has interfered between parent and child, not only in imposing limitation on industrial uses of children, but also to the extent of requiring that children should not be left unvaccinated. It has interfered between employer and employed, to the extent of insisting, in the interests of the latter, that certain sanitary claims shall be fulfilled in all places of industrial occupation. It has interfered between vendor and purchaser; has put restrictions on the sale and purchase of poisons, has prohibited in certain cases certain commercial supplies of water, and has made it a public offence to sell adulterated food or drink or medicine, or to offer for sale any meat unfit for human food. Its care for the treatment of disease has not been unconditionally limited to treating at the public expense such sickness as may accompany destitution: it has provided that in any sort of epidemic emergency organized medical assistance, not peculiarly for paupers, may be required of local authorities; and in the same spirit it requires that vaccination at the public cost shall be given gratuitously to every claimant.

Thus the high noon of free trade and Smilesean individualism was also, paradoxically, the moment at which the state was beginning to make staggering inroads into the traditional freedom of the individual in the name of safeguarding the national health. A battery of different ideologies contributed to breach the citadel of *laissez faire*. Through disciples such as Edwin Chadwick, Bentham's doctrine that the duty of the legislator was to secure the greatest happiness of the greatest number through deploying science, expertise and legal sanctions had its impact, especially in the sanitary domain.<sup>18</sup> In other fields of abuse, particularly those concerning women, children and lunatics, Evangelicalism's moral paternalism overcame the dogmatic defence of hallowed individual rights. And, as recent historians have been concerned to stress, pragmatic pleas of necessity in the teeth of such 'intolerable' evils as cholera disarmed opposition.<sup>19</sup>

It is important to stress that a variety of distinct ideologies, in some ways complementary and in others competing, were applying pressure for state action in particular cases to safeguard the public health. The debates over legislation for sanitation, smallpox, or venereal disease never resulted in simple gross polarisations of opinion – Whigs *versus* Conservatives, religious *versus* secular enthusiasts, the medical establishment *versus* the sick, or whatever. Rather we see internal fractionalisation within each of the powerful parties, professions and interest groups. Each instance – water supply, burial grounds, vaccination – created its new alliances and allegiances, forming and dissolving like clouds on a summer's afternoon, leading to a jerky, uneven development of powers which often reflected the preoccupations of a particular influential reformer – such as Lord Shaftesbury with lunacy law reform – or a pressure group of enthusiasts.

It is in this context that we should interpret the puzzling silence of Mill. Issues such as religious bigotry, cant, and humbug over private morality concentrated and united all his principles and prejudices. By contrast, the issues raised by the public health drive cut confusingly clean across them, as they did for many another Victorian intellectual, physician or civil servant. Mill was deeply wedded both to utilitarianism and to libertarianism. In the long run he believed that they were

totally compatible. In the medium term the causes of happiness, progress, and utility, he contended, would best be served by maximising liberty. Yet (in a way easily seen as casuistical) he was also willing to countenance state intervention, or the infraction of liberties, in certain cases to ensure the effective operation of freedom. Thus no man should be allowed to exercise the 'freedom' of selling himself into slavery, because servitude itself then denied human liberty.

Similarly, Mill believed, the state was duty bound to compel parents to educate their children (despite the interference with the normally sovereign rights of parents), because without education, no young person would be in a position to exercise freedom properly. This approach, which T H Green was soon to call 'hindering hindrances', incorporated a quasi-paternalistic element within the philosophy of liberalism. The state could intervene to protect the liberty of those who could not protect themselves, or it could intervene to improve the lives of those who had abused their liberty. In its various ideological garbs such a doctrine provided a key legitimisation for selective state action (in allegedly exceptional or anomalous cases) amongst those eminent Victorians who deplored Prussian or French bureaucracy and primarily saw themselves as liberal individualists.

Given the strength of encrusted individualism, it should not be surprising that the most dramatic initial inroads into the regular individual right and duty of self-help in health came with a group particularly unable to protect themselves, the insane. The pre-reform era English state had permitted the unchecked growth of a uniquely *laissez-faire* system of managing madness. In most of Continental Europe from the seventeenth century onwards, some form of state authorisation was required for the legal confinement of a mad person by his relatives or friends (in France for example it was by royal *lettre de cachet*; in the United Provinces by order of town authorities).<sup>20</sup>

In England, by contrast, the state had kept completely clear of the trade in lunacy. Till the late eighteenth century anyone could be indefinitely confined in a privately owned madhouse; the transaction was purely private. In 1774, medical certification of the insane and licensing of private madhouses were introduced for the first time.<sup>21</sup> Inspection, however, remained

rudimentary until the establishment of the Lunacy Commission, set up for the metropolitan area in 1828 and extended to the whole country in 1845.<sup>22</sup> Thereafter a state-appointed board, chaired for 53 years by the indefatigable Evangelical, Lord Shaftesbury, vigorously overruled what would otherwise have been the free contractual relationships of the market, and acted on behalf of the putative interests of the insane.

In the case of lunatics, the justification for intervention was simple. By reason of unreason, the insane were legally *non compos mentis*, incapable of minding their own affairs. Legally irresponsible like minors, they needed 'trustees' to act on their behalf. Laws licensing and regulating madhouses and preventing improper confinement would protect the lunatic; in return for that protection, he was to suffer the suspension of his freedom and his civil rights. In time, the range and number of people undergoing certification increased, as the rationales for confinement were enlarged from the initial restrictive one of preventing harm being done by the lunatic to self and others, to the more expansive ideal of therapeutic cure. In other words the state became more interventionist by moving from a 'negative' notion of freedom (preventing harm) to a positive one (doing good). The case of lunacy exemplifies the emergence of the state regulation of health at its most complete and unchallenged.<sup>23</sup>

In the case of preventing infectious disease the ideology of intervention took a somewhat different tack. Here advocates of state medicine, such as John Simon and Henry Rumsey, claimed that what we might call the sovereign right of the individual to contract, die of and spread an infectious disease should be suspended for the benefit of the community as a whole.<sup>24</sup> In this context two sets of legislation were passed during the 1850s and 1860s which made greater inroads than ever before into the civil liberty of individuals to have autonomy over their health and sickness. The Compulsory Vaccination Acts (1853, 1867), placed a legal obligation upon parents to have their children vaccinated within the first year of life; fines or imprisonment were the penalties for default.<sup>25</sup> Compulsory smallpox vaccination constituted a remarkable infringement of the normal rights of parents over their children. For at this time, legal restrictions upon child labour

were few, there was no statutory obligation upon parents to educate their children, and parents still possessed an almost unlimited right to neglect or punish their offspring.<sup>26</sup>

The lunacy laws met little resistance from normally vociferous libertarians. Compulsory smallpox vaccination, however, proved a very different kettle of fish. A powerful opposition lobby was formed, spearheaded by the Anti-Vaccination League (founded in 1867), pressing for repeal. It had numerous strings to its bow. It advanced statistical and medical arguments for the inefficacy – indeed, the gross dangerousness – of vaccination itself. But it also waved the banner of freedom from medical tyranny, some of its members seeing compulsory vaccination as a manifestation of the menace of medical imperialism comparable to the growing practice of vivisection.<sup>27</sup>

Appealing to that cluster of populist and radical interests parading themselves as Davids ranged against the Goliath of the Victorian establishment, the Anti-Vaccination League flexed sufficient muscle power to secure a substantial attenuation of the Acts. A new Act of 1898 permitted parents to opt out if they could prove to a magistrate that they had genuine conscientious objections to the practice of injecting contaminated material into the bodies of their infants.<sup>28</sup> Later in 1907 a further amendment made exemption easier through formal applications to a justice of the peace. The new legislation merely ratified the *status quo* in existing anti-vaccinationist centres, such as Leicester, where the original Act had proved impossible to implement against the wishes of refractory parents, not least because the Union authorities were divided within themselves on the wisdom of vaccination.<sup>29</sup>

Here as elsewhere, in other words, it would be inaccurate to represent the pro- and anti-vaccination campaigns in terms of a simplistic division between authoritarian and libertarian ideologies. The main architect of smallpox legislation after 1856, Sir John Simon, was primarily concerned with ensuring the standard of lymph supply.<sup>30</sup> He was less interested in the stringency of compulsion. For its part, the anti-vaccination lobby was not consistent in its attitudes toward compulsion. While it characterised vaccination as medical despotism, it was prepared to support compulsory notification and isolation in Leicester. The anti-vaccinationists called this the sanitarian's

method, but medical officers of health who operated it hailed it as the triumph of a scientific medical approach to infectious disease and advocated its use in conjunction with vaccination, as in the Gloucester epidemic during 1896.<sup>31</sup>

Compulsory vaccination was one of two pieces of legislation created during the mid-Victorian period aimed at the prevention of infectious diseases. Statutes against venereal diseases formed the other. Legislators – all male of course – essentially accepted that prostitution was a commodity within the market economy, a function of elemental desire. So long as there were men, there would be a demand; so long as there was a market, there would be a supply. Prostitution therefore would inevitably remain a basically unregulated free market activity, subject to sporadic criminal clampdowns. This 'solution' (which had the additional benefit that the state was not 'tainted' by giving sexual vice official license) was quite contrary to the system of policing employed for centuries in many Continental nations, in which prostitution came under administrative jurisdiction through the close licensing of brothels.

The consequence in England was that the chief legislation regarding prostitution attacked it through its alleged threats to health. The Crimean War had revealed that the British army and navy were riddled with venereal disease. To counter this, the euphemistically-named Contagious Diseases Acts (1864, 1866, 1869) formed an attempt to enforce the compulsory medical inspection of street-walkers in specified garrison towns and ports. Women suspected of being common prostitutes could be taken into police custody, subjected to medical examination, and if found venereally infected, detained during the course of treatment.<sup>33</sup>

What is significant, however, is the collapse of the Acts in the teeth of widespread and varied criticism (they were repealed in 1886).<sup>34</sup> As with the anti-vaccination lobby, opposition to the Contagious Diseases Acts formed into societies, such as the National Anti-Contagious Diseases Association (1869), led by Josephine Butler, which won the support of a range of radical elements battling against what they saw as the unjustifiable encroachments upon civil liberties. Libertarian arguments against the Acts were advanced; even the *British Medical*

*Journal* initially denounced them on the grounds that they infringed the 'civil rights' of prostitutes.<sup>35</sup> Medico-scientific arguments were added: the Acts (it was alleged) were bound to prove ineffective in reducing venereal diseases. And most powerfully of all, perhaps, a moral groundswell stigmatised the Acts, with their quite explicit avowal of the sexual 'double standard', both as deeply offensive to women and as condoning vice (by making for 'safe' promiscuous sex for libertine males).<sup>36</sup>

There is no denying that a vocal section of the medical profession – army and navy doctors in particular – supported the Acts as an effective attack upon venereal disease, backing their case with an ingrained medical mysogyny. Other doctors, including no less an eminence than Sir John Simon, expressed considerable reservations when their extension was proposed, being unwilling to embroil the profession in the disreputable business of acting as moral gaolers.<sup>37</sup> Neither can one find a simple libertarian/authoritarian polarisation in the minds of the repealers. For many members of the Ladies National Association, the 'liberal' campaign to spare prostitutes from the police and the 'instrumental rape' of the surgeon broadened into a revivalist social purity campaign, eventually organised in the National Vigilance Movement, to 'protect' women by introducing legal restrictions aimed at outlawing prostitution. 'Votes for women, chastity for men' became Christabel Pankhurst's suffragette rallying call.<sup>38</sup>

The argument which justified the prevention of infectious diseases through compulsory health legislation claimed that the well-being of the community took priority over the autonomy of the individual in respect of health and sickness. Repeal organisations objected to the invasion of the body by the state:

Against the body of a healthy man Parliament has no right of assault whatever under pretence of the Public Health; nor any the more against the body of a healthy infant... The law is an unendurable usurpation, and creates the right of resistance.<sup>39</sup>

The easiest place to insert the thin edge of the wedge of compulsory intervention in health was into the bodies of those

who were least able to protest. Then the interventionist state achieved its aim under the guise of paternalism, protecting those unable to protect themselves – lunatics, and children (in the case of vaccination) – and it finally moved to protecting society against a section of its supposedly least responsible elements – the criminal fringe, and prostitutes.

It is often alleged nowadays – indeed, in the case of AIDS itself – that governments (particularly governments of the Right) irresponsibly whip up scaremongering ‘moral panics’ which they then exploit to introduce repressive legislation dressed up in the ‘sanitised’ language of public health.<sup>40</sup> The compulsory smallpox vaccination legislation and the Contagious Diseases Acts just examined indicate a rather different scenario. For in both these cases, the legislation itself was passed in the absence of noisy public panic-making, but rather as a result of a small band of committed public health advocates (one could call them ‘technocrats’), politicians and civil servants, diplomatically pushing a bill – in the case of the vaccination act, a private member’s bill – through the House with minimal discussion. The *grande peur* was in fact created by *repealers* who, in the case of smallpox, argued that vaccination (injecting morbific matter) was more liable to create, than to prevent, smallpox epidemics, and in the case of prostitution, claimed that no honest woman was now safe from suspicion.

The successes of the repeal campaign in both cases is a sign of the relative fragility of the alliance between government and the organised medical profession, and of deep internal divisions within both as to the propriety, practicality and prudence of the enforcement of health. No Victorian government was prepared to take its commitment to preventive medicine to the point of risking great unpopularity. Equally, the scions of the medical profession – above all the Royal Colleges of Physicians and Surgeons – were keen to preserve their own independence and to keep government at arm’s length.

It is significant then that the major instance of the successful introduction of compulsory powers over adults in the sphere of public hygiene and preventive medicine should have come very late in the century, should have initially been adoptive only, and should have been associated with local agencies. This

lay in the development of the idea of notifiable diseases, that is, those socially infectious diseases which proved such a hazard in the Victorian urban environment.

Under the Local Government Act of 1875, medical officers of health were granted powers to remove sufferers from such diseases out of the community and place them in isolation or fever hospitals, as 'nuisances'. This procedure was taken one stage further by the Notification of Diseases Act of 1889 (adoptive) and 1899 (compulsory: still in modified form in force today). This rendered obligatory the notification to the medical officer of health of any incidence of a list of specified contagious diseases, including typhus, typhoid, smallpox, erysipelas, scarlet fever, enteric fever and the like. The MOH was subsequently empowered to remove the patient to an isolation hospital and detain him there for treatment until he was rendered non-infectious, and to disinfect the original site of infection.<sup>41</sup>

In some ways this legislation represents a striking infringement of the traditional freedom to be sick, and indeed to spread one's sickness, with impunity.<sup>42</sup> But there was no organised opposition to it. The greatest contention lay, instead, between the preventive and clinical branches of the medical profession itself. Thomas Crawford, the president of the Sanitary Institute, expressed in 1895 a common feeling of resentment among his clinical colleagues concerning the way the medical officers of health operated the notification system in their localities. The procedure of secondary (bacteriological) diagnosis undermined the authority of the general practitioner with his patients. Worse still, the detection and threat of prosecution for default of notification infuriated GPs who considered it an affront to their integrity.<sup>43</sup> The insult was particularly barbed when the MOH himself also continued in part-time general practice, and his own position in the local medical marketplace was improved as a by-product of the notification system. Crawford claimed that dissatisfaction was also felt by patients and their families:<sup>44</sup>

The English people are not afraid of risking either their lives or their health in the interests of those whom they love and they are consequently not easily persuaded to part with any

member of their family simply because he or she happens to be suffering from an infectious disease.

The response of MOHs was to dismiss the idea of family objections as fictitious. They cited the example of the Metropolitan Asylum Board which was overburdened by the demand for isolation and its costs, simply because most patients were glad to spend time in hospital when they were severely sick with an infectious disease. But they admitted to the open hostility expressed by GPs and acknowledged that the success of the system depended a great deal on the tact and diplomacy of individual officers.<sup>45</sup>

It is noteworthy that it met with so little public opposition, given that when comparable powers of removal had first been introduced during the 1832 cholera epidemic, there had been extensive rioting against the government measures (partly on the ground that cholera was what Cobbett called a 'humbug' put about to distract attention from the new Poor Law).<sup>46</sup> It suggests that by the last quarter of the nineteenth century, the public was softening or acclimatising to a new medical rationality which might involve the trimming of its liberties.<sup>47</sup>

For reasons initially more connected with improved nutrition and a healthier environment than with innovations in curative medicine, the infections which had constituted such a health hazard in earlier centuries gradually ceased to pose such a threat. The Notification of Diseases Acts still remain on the statute books but mercifully rarely have to be invoked. It is perhaps then not surprising that the key debates this century upon the propriety and necessity of compulsory powers for the prevention and treatment of disease have centred upon venereal disease. New methods of detecting and curing syphilis with the development of the Wasserman test in 1907 and Ehrlich's development of Salvarsan in 1910 revived a preoccupation with reducing the considerable prevalence of the disease.<sup>48</sup> One estimate claimed that anything up to half-a-million Londoners were infected<sup>49</sup>, and the advent of war in 1914 and 1939 fuelled fears that concentrations of soldiers and wartime morality would swell the disease to epidemic proportions and jeopardise the fighting capacity of the armed forces.

A Royal Commission was set up in 1913 to investigate the possible development of a future VD service, and made its report in 1916.<sup>50</sup> From the outset the failures of the Contagious Diseases Acts were acknowledged and a return to them was discounted by the Commissioners. This represents to some degree a shift of opinion, especially regarding prostitution. Prostitutes were no longer regarded as the major source of infection; rather the fact that increasing numbers of 'ordinary' as well as 'professional' women were abandoning chaste sexual behaviour meant that the 'amateur' now posed a far greater danger – and one which was much more difficult to detect.<sup>51</sup>

The Commission made an important discrimination between the prevention of socially and sexually transmitted diseases. The former were visible and necessitated treatment in their earliest stages; the latter lay dormant and difficult to detect. Sexually transmitted diseases remained contagious without presenting life-threatening symptoms to the carrier. The Commission's report acknowledged the need for early detection and treatment to prevent spread. This required, most significantly, the cooperation of the patients themselves, firstly to present their symptoms and then continue with treatment until cured and rendered non-infectious. It concluded that the stigma attached to official notification would militate against an efficient system of control. Cooperation depended upon the confidentiality between doctor and patient. Breaking this would alienate clinicians and their patients, driving venereal disease underground to the quack operators and their remedies.<sup>52</sup>

A separate system of VD clinics, for men and for women, was to be established. Attendance would be voluntary. Anonymity and confidentiality would be preserved (and for that reason, the clinics were to have no formal connections with general practitioners and hospitals). Attenders would be encouraged, but not compelled, to inform sexual contacts. Treatment would be free. It was a system which would 'condone vice' no less than the Contagious Diseases Acts. But – a sign of the times – it condoned male and female vice equally, and involved no stigmatisation of prostitutes. The underlying philosophy was to create a climate which would encourage maximum cooperation and attendance among patients.<sup>53</sup> The Commission's findings were translated into new Local Government

Board regulations issued in July 1916 and incorporated into a Venereal Disease Act in 1917.<sup>54</sup> The Commission recommended that the National Council for Combating Venereal Disease, formed in 1914, be adopted as the official body to undertake an education campaign. The NCCVD, later to become the British Social Hygiene Council, subsequently continued with a propaganda lecture programme among the troops and civilian population together with poster campaigns and documentary films.<sup>55</sup>

Venereal disease did not disappear. But it was thereby contained at a manageable level. This was due in part to the new diagnostics and therapeutics. Partly it was because the clinics themselves proved quite successful, in conjunction with education campaigns mounted by the Social Hygiene Council. The Trevethin Committee, which examined the working of the new clinics in 1923, agreed that their visible success demonstrated that compulsory notification was not the answer.<sup>56</sup> Notification, it was pointed out, could not possibly be effective unless backed by the ultimate sanction of compulsory detention, and that would prove unacceptable.

Similar arguments were bruited at the time of the Second World War, which produced expectations of a new wave of venereal disease (there was an initial rise between 1939–41 and a slower but steady increase from 1941–2, after which the rates declined).<sup>57</sup> The rival merits of a voluntary system and a compulsory one were once more debated. This time, advocates of compulsion, including prominent members of the Medical Society for the Study of Venereal Diseases, could point to its systematic application since 1915 in the social democratic atmosphere of public-health conscious Sweden and Holland, where compulsory notification and treatment were legally enforced. In England itself the radical-activist medical ginger group, the Society for the Prevention of Venereal Disease, had been calling since the 1920s for a mixed package which would include the ready availability of prophylactics in shops alongside compulsory notification, treatment and isolation.<sup>58</sup>

Critics, however, were not convinced. They deplored excessive regulation (*The Lancet* had earlier complained that the Swedish legislation 'bristles with penalties'), cast doubt on the success of the Swedish system, and argued in any case that

controls (for example, contact tracing) which would work in Sweden's small population would hardly prove successful in densely populated, mobile, urbanised England. In any case, once again, leading members of the medical profession came out strongly against compulsory notification (it was 'not British' some said), displaying their own distaste for becoming overclosely involved in a system of administrative coercion. Compulsion, it was widely argued, 'struck at the root of the relationship of trust and confidence between doctor and patient'; it would, moreover, open the door to blackmail. Overall, doctors, it was alleged, would 'not comply' with such a system, which 'smacked of Hitlerite Germany'.<sup>59</sup> Physic and police should not be unwisely mingled.

The medical profession came out strongly in favour of the existing system of voluntary clinics. Its efficacy could best be improved by free and frank educational campaigns, removing shame and the conspiracy of silence, and putting VD on an equivalent footing to every other disease. The Social Hygiene Council was authorised to instigate a programme of publicity (though the medical press often complained about the mealy-mouthedness of the wording of the advertisements which actually appeared).<sup>60</sup>

One concession to compulsion was however introduced. A new emergency Regulation 33B added to the Defence (General) Regulations in 1942 stated that compulsory treatment could be instituted against any contact named by two or more sufferers. This was seen as, and was used as, a way of instituting proceedings against infected prostitutes, and so became, as Dr Edith Summerskill complained, a small-scale and roundabout reintroduction of the double standards of the Contagious Diseases Acts. It became a dead letter after the end of the War.<sup>61</sup>

The analysis offered by this paper has demonstrated that interfaces between the state and medical practice have grown up since the mid-nineteenth century. The state made greatest inroads into the freedom of individuals in giving asylum to the mentally ill and preventing infectious disease.

The legal basis for the operation of the notification laws and the incarceration of the mentally disturbed has been a form of internment without trial. To reduce levels of infectious disease

the state has suspended the right of *habeas corpus*, in order to prevent an individual from infecting his fellow citizens. This suspension of liberty was justified by the advocates of state medicine on the grounds that the period of deprival of freedom was limited and that hospitalisation would maximise chances of cure; but, most importantly it was argued that the community at large would benefit from the reduction of the risk of epidemics.

In the case of diseases which are transmitted through ordinary social contact the aim was to prevent dissemination, since the sufferer spreads infection by his very presence among the healthy. In the case of sexually transmitted diseases the patient, once informed of his condition, cannot spread the disease unless he deliberately chooses to do so. After 1916 those who argued for compulsory treatment and detention of VD patients offered statistics to suggest that high levels of default – refusal or failure to complete treatment – indicated that the system could not be entrusted to their voluntary cooperation. Those who argued against compulsion claimed that the statistics for default did not differ greatly between voluntary and compulsory systems; and, indeed, default would increase if confidentiality was breached. Thus, in the twentieth century, the argument concerning prevention moved from disease to default.

The balance between individual liberty and the higher public good espoused by the prevention of disease was recognised by the Victorians to be a delicate one. Securing the health of the community frequently depended not so much on philosophical discourse but on the balance – or imbalance – of power between preventive and curative medicine. The argument which eventually won the day in the British context for the non-notification of sexually transmitted diseases had less to do with personal liberty than with the power of the clinical profession to maintain the private, contractual relationship with the individual patient as the jewel in the crown of medical practice. Medical officers of health and practitioners of community medicine have consistently remained the Cinderellas of the profession in contrast to the consultants and the clinicians. These legacies of a bygone age help to explain why the enforcement of health has always been, and remains, a low priority for the medical profession.

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## EQALYTY

John Harris

If we choose *not* to provide someone with the care or treatment that he or she needs in order to stay alive then, if he or she dies, we are responsible for that person's death.<sup>1</sup> Of course we may have, (or we may believe we have) no choice. Where resources are scarce we may have literally to choose who shall live and who shall die, and it may be (will be) quite impossible to prevent the deaths of all those whose deaths are preventable. But of course while we may not be able to provide treatment for everyone who needs it, we can usually choose which of those in need to help. This choice, inevitable though it may be, will have consequences for which we are responsible. Since these consequences will include the premature deaths of some individuals, it is important that such choices are made scrupulously.

In this chapter I want to say something about what it is to make a scrupulous choice in these circumstances, and to do so principally by evaluating one increasingly influential answer to this question. In doing so I shall attempt to set out the most important moral considerations that constrain these choices, and particularly which set limits to the political, economic and medical reasons that may be advanced for preferring to save some individuals rather than others.

Against a background of permanently scarce resources it is clearly crucial that such health care resources as are available are not used wastefully. This point is often made in terms of

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'efficiency' and it is argued, not implausibly, that to talk of efficiency implies that we are able to distinguish between efficient and inefficient use of health care resources, and hence that we are in some sense able to measure the results of treatment. To do so, of course, we need a standard of measurement. Traditionally, in life endangering conditions, that standard has been easy to find. Clearly, successful treatment removes the danger to life, or at least postpones it, and so the survival rates of treatment have been regarded as a good indicator of success.<sup>2</sup> However, equally clearly, it is also of crucial importance to those treated that the help offered them not only removes the threat to life, but leaves them able to enjoy the remission granted. In short, gives them reasonable quality as well as extended quantity of life.

A new measure of quality of life which combines length of survival with an attempt to measure the quality of that survival has recently been suggested and is becoming influential.<sup>3</sup> The need for such a measure has been thus described by one of its chief architects: 'We need a simple, versatile, measure of success which incorporates both life expectancy and quality of life, and which reflects the values and ethics of the community served. The "quality adjusted life year" (QALY) measure fulfils such a role.'<sup>4</sup> This is a large claim and an important one. If it can be sustained its consequences for health care will be profound indeed.

There are however substantial theoretical problems in the development of such a measure and, more important by far, grave dangers of its misuse. I shall argue that the dangers of misuse, which partly derive from inadequacies in the theory which generates it, make this measure itself a life threatening device. It is to the task of showing just why this is so that we must now turn. A task incidentally which, because it aims at the identification and eradication of a life threatening condition, itself (surprisingly perhaps for a philosophical paper) counts also as a piece of medical research<sup>5</sup> which, if successful, will prove genuinely therapeutic.

## The QALY

### *1. What are QALYs?*

It is important to be as clear as possible as to just what a QALY is and what it might be used for. I cannot do better than let Alan Williams, the architect of QALYs referred to above, tell you in his own words:

The essence of a QALY is that it takes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the 'quality adjusted' bit is all about). If being dead is worth zero, it is, in principle, possible for a QALY to be negative, ie for the quality of someone's life to be judged worse than being dead.

The general idea is that a beneficial health care activity is one that generates a positive amount of QALYs, and that an efficient health care activity is one where the cost-per-QALY is as low as it can be. A high priority health care activity is one where the cost-per-QALY is low, and a low priority activity is one where cost-per-QALY is high.<sup>6</sup>

The plausibility of the QALY derives from the idea that 'given the choice, a person would prefer a shorter, healthier life to a longer period of survival in a state of severe discomfort and disability.'<sup>7</sup> The idea that any rational person would endorse this preference provides the moral and political force behind the QALY. Its acceptability as a measurement of health then depends upon its doing all the theoretical tasks assigned to it, and on its being what people want, or would want, for themselves.

### *2. How will QALYs be used?*

There are two ways in which QALYs might be used. One is unexceptionable and useful, and fully in line with the assumptions which give QALYs their plausibility. The other is vicious and indefensible.

QALYs might be used to determine which of rival therapies

to give to a particular patient or which procedure to use to treat a particular condition. Clearly the one generating the most QALYs will be the better bet, both for the patient and for a society with scarce resources. However, QALYs might also be used to determine not what treatment to give these patients, but which group of patients to treat, or which conditions to give priority in the allocation of health care resources. It is clear that it is this latter use which Williams has in mind, for he specifically cites as one of the rewards of the development of QALYs, their use in 'priority setting in the health care system in general'.<sup>8</sup> It is this use which is likely to be of greatest interest to all those concerned with efficiency in the health service. And it is for this reason that it is likely to be both the most influential and to have the most far-reaching effects. It is this use which is indefensible. Why?

### 3. *What's wrong with QALYs?*

It is crucial to realise that the whole plausibility of QALYs depends upon our accepting that they simply involve the generalisation of the 'truth'<sup>9</sup> that 'given the choice a person would prefer a shorter healthier life to a longer period of survival in a state of severe discomfort'. On this view giving priority to treatments which produce more QALYs or for which the cost-per-QALY is low, is both efficient and is also what the community as a whole, and those at risk in particular, actually want. But whereas it follows that given the choice a person would prefer a shorter healthier life to a longer one of severe discomfort and that the best treatment *for that person* is the one yielding the most QALYs, it does not follow that treatments yielding more QALYs are preferable to treatments yielding fewer where *different people* are to receive the treatments. While it follows from the fact (if it is a fact) that I and everyone else would prefer to have, say, one year of healthy life rather than three years of severe discomfort and that we value healthy existence more than uncomfortable existence for ourselves, it does not follow that where the choice is between three years of discomfort or immediate death for *me* and one year of health or immediate death for *you*, that I am somehow committed to the judgment that you ought to be saved rather than me.

Suppose that Andrew, Brian, Charles, Dorothy, Elizabeth, Fiona and George all have zero life expectancy without treatment, but with medical care all but George will get one year's complete remission and George will get seven years' remission. The costs of treating each of the six are equal but George's operation costs five times as much as the cost of the other operations. It does not follow that even if each person, if asked, would prefer seven years' remission to one for themselves, that they are all committed to the view that George should be treated rather than that they should. Nor does it follow that this is a preference that society should endorse. But it is the preference that QALYs dictate.

Such a policy does not value life or lives at all, for it is individuals who are alive and individuals who lose their lives. The value of someone's life is, primarily and overwhelmingly, its value to him or her; the wrong done when an individual's life is cut short is a wrong to that individual. The victim of a murder or a fatal accident is the person who loses his life. A disaster is the greater the more victims there are, the more lives that are lost. A society which values the lives of its citizens is one which tries to ensure that as few of them die prematurely (that is when their lives could continue) as possible. Giving value to life years or QALYs has the effect in this case of sacrificing six lives for one. If each of the seven *wants* to go on living for as long as he or she can, if each values the prospective term of remission available, then to choose between each of them on the basis of life years, (quality adjusted or not) is in this case to give no value to the lives of six people.

#### *4. The ethics of QALYs*

Although we might be right to claim that people are not committed to QALYs as a measurement of health simply in virtue of their acceptance of the idea that each would prefer to have more QALYs rather than fewer for themselves, are there good moral reasons why QALYs should none the less be accepted?

Williams suggests that QALYs involve the idea that 'one year of healthy life is of equal value no matter who gets it', and that each person's valuations 'have equal weight', but is this so?

We have seen how the idea that 'one year of healthy life is of equal value no matter who gets it' could mean one person collaring all the QALYs available – for if it doesn't matter who gets it, it doesn't matter that one person has 30 rather than that 30 other people have one each. So, the claim that each individual's valuations are to have 'equal weight' means that people's lives, as opposed to their QALYs, are in fact valued at nothing.

This happens because the idea, which is at the root of both democratic theory and of most conceptions of justice, that each person is as morally important as any other and, hence, that the life and interests of each is to be given equal weight, while apparently referred to and employed by Williams, plays no part at all in the theory of QALYs. That which is to be given equal weight is not persons and their interests and preferences, but quality adjusted life years. And giving priority to the manufacture of QALYs can mean them all going to a few at the expense of the interests and wishes of the many. It will also mean that all available resources will tend to be deployed to assist those who will thereby gain the maximum QALYs – the young.

### 5. *The fallacy of valuing time*

There is a general problem for any position which holds that time-spans are of equal value no matter who gets them, and it stems from the practice of valuing life units (life years) rather than people's lives.

If what matters most is the number of life years the world contains, then the best thing we can do is devote our resources to increasing the population. Birth control, abortion and sex education come out very badly on the QALY scale of priorities.

In the face of a problem like this, the QALY advocate must insist that what he wants is to select the therapy that generates the most QALYs for those people who already exist, and not simply to create the maximum number of QALYs. But if it is people and not units of life-span that matter, if the QALY is advocated because it is seen as a moral and efficient way to fulfil our obligation to provide care for our fellows, then it does

matter who gets the QALYs – because it matters how people are treated. And this is where the ageism of QALYs and their other discriminatory features become important.

#### *6. QALYs are ageist*

Maximising QALYs involves an implicit and comprehensive ageist bias. For saving the lives of younger people is, other things being equal, always likely to be productive of more QALYs than saving older people. Thus on the QALY arithmetic we always have a reason to prefer, for example, neonatal or pediatric care to all 'later' branches of medicine. This is because any calculation of the life years generated for a particular patient by a particular therapy must be based on the life expectancy of that patient. The older a patient is when treated, the fewer the life years that can be achieved by the therapy.

It is true that QALYs dictate that we prefer people not simply who have *more life expectancy* but rather people who have *more life expectancy to be gained from treatment*. But wherever treatment saves a life – and this will be frequently, for quite simple treatments, like a timely antibiotic, can be life saving – it will, other things being equal, be the case that younger people have more life expectancy to gain from the treatment than older people.

The essentially ageist feature of QALYs is of the first importance for it demonstrates that what appears at first sight to be a major advantage of QALYs, namely their impartiality, is an illusion. So far from being essentially impartial they are essentially age biased. Moreover, this bias may operate in other ways also.

#### *7. QALYs favour cheaply and easily treated conditions*

If a 'high priority health care activity is one where the cost-per-QALY is low, and a low priority activity is one where cost-per-QALY is high' then people who just happen to have conditions which are relatively cheap to treat are always to be given priority over those who happen to have conditions which are relatively expensive to treat. This will inevitably

involve not only a systematic pattern of disadvantage to particular groups of patients, or to people afflicted with particular diseases or conditions, but perhaps also a systematic preference for the survival of some kinds of patients at the expense of others. We usually think that justice requires that we do not allow certain sections of the community or certain types of individual to become the victims of systematic disadvantage and that there are good moral reasons for doing justice, not just when it costs us nothing or when it is convenient or efficient, but also and particularly, when there is a price to be paid. We shall return shortly to this crucial issue of justice, but it is important to be clear about the possible social consequences of adopting QALYs.

In addition to favouring those conditions which are cheap to treat or easy or straightforward to ameliorate, QALYs may also favour in some circumstances certain races or one gender over another. I do not want to make too much of this point for it is a minor one. None the less it is worth just noting it for the record at this stage.

#### *8. QALYs can be racist and sexist*

Adoption of QALYs as the rationale for the distribution of health care resources may, for the above reasons, involve the creation of a systematic pattern of preference for certain racial groups or for a particular gender or, what is the same thing, a certain pattern of discrimination against such groups. Suppose that medical statistics reveal that, say, women, or Asian males do better than others after a particular operation or course of treatment. Or that a particular condition that has a very poor prognosis in terms of QALYs afflicts only Jews or gay men. Such statistics abound and the adoption of QALYs may well dictate very severe and systematic discrimination against groups identified primarily by race, gender or colour in the allocation of health resources, where it turns out that such groups are vulnerable to conditions that are not QALY efficient.<sup>10</sup>

Of course it is just a fact of life and far from sinister that different races and genders are subject to different conditions, but the problem is that QALYs may tend to reinforce and

perpetuate these 'structural' disadvantages. We should therefore be wary of a device which might lead us almost automatically to allocate resources in ways which might perpetuate already entrenched injustice.

### *9. Double jeopardy*

Relatedly, suppose a particular terminal condition was treatable and would, with treatment, give indefinite remission but with a very poor quality of life. Suppose, for example, that if an accident victim were treated he would survive but be paraplegic. This might always work out at fewer QALYs than a condition which with treatment would give a patient perfect remission for about five years after which the patient would die. Suppose that both candidates wanted to go on living as long as they could and so both wanted, equally fervently, to be given the treatment that would save their lives. Is it clear that the candidate with most QALYs on offer should always and inevitably be the one to have priority? To judge so would be to count the paraplegic's desire to live the life that was available to him as of less value than his rival's. And surely equal weight should be given to the preferences of each individual.

This feature of QALYs involves a sort of double jeopardy. QALYs dictate that because an individual is unfortunate, because he or she has once become a victim of disaster, we are required to visit upon him or her a second and perhaps graver misfortune. The first disaster leaves the patient with a poor quality of life and QALYs then require that because of this he or she be ruled out as a candidate for life saving treatment or, at best, that he or she be given little or no chance of benefiting from what little amelioration the condition allows.

The first disaster leaves the patient with a poor quality of life and when he or she comes forward for help, along come QALYs and finish him or her off!

We are now in a position to see that one superficially attractive feature of QALYs is in fact less than convincing.

### *10. Justice*

At first glance it might seem that a Rawlsian<sup>11</sup> conception of justice might favour QALYs. For if we were to decide which

method of resource allocation to adopt when we did not know how our personal circumstances would be affected by the chosen method of distribution (behind a 'veil of ignorance'), we might well decide that health care should be allocated on a QALY basis. That way each one of us would maximise our chances of the greatest number of QALYs, which it is plausible to suppose would be what we want for ourselves. And of course this is in a sense just what QALYs do, for few of us know what health care resources we will need when we decide whether or not QALYs should constitute the method of allocation.

However, a Rawlsian approach is unlikely to favour QALYs for two reasons. The first is that while people would certainly want the therapy which yields the most QALYs when choosing for themselves between rival therapies, they would be unlikely to want a method of selecting people for care which would maximise *life years* rather than *lives saved*. For unless they were very young, their chances of benefiting from such a method of distribution would not be maximal and they would be unlikely to want automatically to give way to rivals with greater life expectancy. Each person would have less chance of benefiting in a QALY system than they would in a system where each person counted as one. True, if they did benefit they would be likely to benefit more, but whether rational, self interested individuals would opt for a system in which their chances of benefiting were significantly less than they might be is surely doubtful.

Perhaps of equal importance is the fact that QALYs violate one of Rawls' fundamental principles of justice – that inequalities in such things as power, wealth, income and other resources, including health resources, are impermissible except if they work to the absolute benefit of *the worst-off members of society*. But of course QALYs have the reverse effect: instead of operating to the absolute benefit of the worst-off members of society, they operate to their absolute detriment. For the worst-off members are those with the poorest quality of life coupled with the poorest life expectancy.

These two features of QALYs taken together make them unlikely to prove appealing to those attracted to a Rawlsian view of justice.

### *11. Life saving and life enhancing*

A distinction should be made between treatments which are life saving (or death postponing) and those which are simply life enhancing, in the sense that they improve the quality of life without improving life expectancy. Most people think, and for good as well as for prudential reasons, that life saving has priority over life enhancement and that we should first allocate resources to those areas where they are immediately needed to save life; only when this has been done should the remainder be allocated to alleviating non-fatal conditions. Of course there are exceptions even here and some conditions, while not life threatening, are so painful that to leave someone in a state of suffering while we attend even to the saving of life, would constitute unjustifiable cruelty. But these situations are rare and for the vast majority of cases we judge that life saving should have priority.

It is important to note that QALYs make no such distinction between types of treatment. For the removal of, say, conditions involving non-fatal but significant discomfort, in classes of patients with long life expectancy, will generate more QALYs than saving the lives of patients with shorter life expectancy. Treating eczema in teenagers or dysmenorrhea in young women might for example be more QALY efficient than resuscitating old people who are victims of cardiac arrest.

Clearly there is something fishy about QALYs. They can hardly form 'an appropriate basis for health service policy'. Can we give an account of just where they are deficient from the point of view of morality? We can, and indeed we have already started to do so. In addition to their other problems, QALYs and their use for priority setting in health care or for choosing not only which treatment to give patients but also selecting which patients or conditions to treat, involve profound injustice. If QALYs are implemented they would constitute a denial of the most basic civil rights. Why is this?

#### **Moral constraints**

I should make it clear that I am not suggesting that we cannot choose between lives. I realise that health care professionals

have to make such decisions all the time. But where the need for a decision is dictated by scarce resources (where, but for scarce resources, a person or condition could be given beneficial treatment) then the decision is not medical nor economic nor even political, but moral. And though a democratic society has the *power* through its elected representatives to do what it chooses, it ought not to choose to do what is morally wrong.

The defects in the arguments for the use of QALYs as measurements of the relative value of different types of therapy have revealed a more fundamental difficulty in using any measures of the value or quality of life when choosing between lives, or when deciding how to allocate scarce resources. This difficulty turns on an understanding of the moral constraints governing such decisions.

One general constraint that, I think, most people would judge should govern such decisions is the belief that the life and health of each person matters, and matters as much as that of any other. Each person is entitled to be treated with equal concern and respect both in the way health resources are distributed and in the way they are treated generally by health care professionals, however much their personal circumstances may differ from those of others.

This popular belief about the values underlying the health service depends on a more abstract view about the source and structure of such values and it is worth saying just a bit about this now.

### *1. The value of life*

One such value is the value of life itself. Our own continued existence as individuals is the *sine qua non* of almost everything. As long as we want to go on living, practically everything we value or want depends upon our continued existence. This is one reason why we give priority to life saving over life enhancing.

In most circumstances, the worst thing that can happen to an individual is that he or she loses his or her life when this need not happen. And the worst thing we can do is make decisions which result in others dying prematurely. Therefore, we must

think that *each life is valuable*; that each life counts for one and that is why more count for more. For this reason we should give priority to saving as many lives as we can, not as many life years.<sup>12</sup>

## 2. *Treating people as equals*

If each life counts for one, then the life of each has the same value as that of any. This is why accepting the value of life generates a principle of equality. This principle does not of course entail that we treat each person equally in the sense of treating each person *the same*. This would be absurd and self-defeating. What it does involve is the idea that we treat each person with the same concern and respect. An illustration provided by Ronald Dworkin, whose work on equality informs this entire discussion, best illustrates this point: 'If I have two children, and one is dying from a disease that is making the other uncomfortable, I do not show equal concern if I flip a coin to decide which should have the remaining dose of a drug.'<sup>13</sup>

It is not surprising, then, that we think of protection for individuals in terms of civil rights<sup>14</sup> which centre on the physical protection of the individual and of his or her most fundamental interests. One of the prime functions of the state is to protect the lives and fundamental interests of its citizens and to treat each citizen as the equal of any other. This is why the state has a basic obligation, *inter alia*, to treat all citizens as equals in the distribution of benefits and opportunities which affect their civil rights. The state must, in short, treat each citizen with equal concern and respect. The civil rights generated by this principle will of course include rights to the allocation of such things as legal protection and educational and health care resources. And this requirement means that the state must not choose between individuals, or permit choices to be made between individuals, that abridge their civil rights or affect their right to treatment as equals.

Whatever else this means, it certainly means that society, through its public institutions, is not entitled to discriminate between individuals in ways that mean life or death for them on grounds which attack their right to treatment as equals; that is,

on grounds which count the lives or fundamental interests of some as worth less than others. If, for example, some people were given life saving treatment in preference to others because they had a better quality of life, or more dependants and friends, or because they were considered more useful, this would amount to regarding such people as more valuable than others on that account. Indeed, it would be tantamount, literally, to sacrificing the lives of others so that the favoured individuals might continue to live.

Because my own life would be better and of even more value to me if I were healthier, fitter, had more money, more friends, more lovers, more children, more life expectancy, more everything I want, it does not follow that others are entitled to decide that because I lack some or all of these things I am less entitled to health care resources, or less worthy to receive those resources, than are others, or that those resources would somehow be wasted on me.

### *3. Civil rights*

I have spoken in terms of civil rights advisedly. If we think of the parallel with our attitude to the system of criminal justice the reasons will be obvious. We think that the liberty of the subject is of fundamental importance and that no one should be wrongfully detained. This is why there are no financial constraints on society's obligation to attempt to ensure equality before the law. An individual is entitled to a fair trial no matter what the financial costs to society (and they can be substantial). We don't adopt rubrics for the allocation of justice which dictate that only those for whom justice can be cheaply provided will receive it. And the reason is that something of fundamental importance is at stake – the liberty of the individual.

In health care something of arguably greater importance is often at stake – the very life of the individual. Indeed, since the abolition of capital punishment, the importance of seeing that an individual's civil rights are respected in health care is pre-eminent.

#### *4. Alternative quality considerations*

I think and hope that I have said enough to cast grave doubts on the morality of QALYs, and on their attractiveness as a method of distributing health care resources. In doing so I have also and more obliquely attacked other, not specifically QALY-relevant, ways of discriminating between candidates for care; ways which are, however, related to QALYs in that they employ 'quality of life' criteria. The QALY is based principally on the Rosser<sup>16</sup> disability scales which measure quality of life primarily in terms of the level of distress supposedly occasioned by a combination of disability, impairment of function and lack of mobility. QALYs combine these features with life expectancy to generate the QALY. However, other quality of life measures are commonly, if less overtly and explicitly, used to justify discrimination between candidates for health care. They separate conveniently into considerations that have purely to do with quality of life and those which have to do with life expectancy, and we'll look at them in turn and briefly.<sup>17</sup>

#### *5. Third party interests*

It is sometimes suggested that those with dependants or friends should, other things being equal, be given priority over the childless or friendless in the allocation of rescue or health care. But this way of allocating resources carries with it the danger of creating a community in which some citizens are effectively valued more than others. Those who favour such selective distribution usually believe that while 'this seems obviously objectionable if our preference is based on the belief that one of the people is nicer, more intelligent or morally superior to the other person ... the objection loses a lot of its force when the preference is justified by citing the interests of dependants rather than the merits of the person selected'.<sup>18</sup> I am not sure that the objection to quality control on the grounds that it creates first and second class citizens and consequently involves unjust selection can be so easily overcome. For one thing, although we can recognise that children and friends will be adversely affected by the death of a loved one, by far the

greatest loss is to the deceased. It seems not only unjust but counterproductive to inflict this loss systematically on the childless or the friendless – as unjust as it would be to grade people in any other way. It seems less than convincing to suggest that concentration on the interests of dependants, rather than on the merits of individuals, rescues such a policy from the opprobrium of an arbitrary division of society into grades of people with priority always and automatically accorded to those with families.

For those who like their justice tempered with self-interest it is also likely to be counter-productive. If systematic family preference became overt public policy it might begin to seem that a relatively cheap form of health insurance – insurance against a low priority rating in the quality control mechanism of society – would be the acquisition of a family. Of course one would have to make sure that one spaced one's children so as always to have at least one dependant on hand, and took steps to ensure that one's dependants did not for example defect to enhance the quality quotient of an estranged spouse. This might lead to more durable marriages or more bitterly contested custody suits with perhaps one parent's life literally at stake on the outcome. Whether on balance we would find such arrangements morally preferable to a situation in which children took pot luck on the survival of their parents, and no one's life was discounted in favour of another merely because they could not produce the requisite quota of dependants, seems to me doubtful.

We should also remember that the practice of counting third party preferences or interests is double edged. If it is supposed that the fact that I have a wife and child who want me to live and would be distressed if I died, is a reason to save me rather than you, if their favourable interest in my life and health is to count in my favour, it follows that if I have a wife and child who wish me dead and would be delighted at my demise, then this is a fact that counts against me and in favour of a lone stranger. If we do not like the idea of third party preferences counting against someone, we should remember that this is just what happens if we allow third party interests to count in someone's favour. For if my children want me to live, and it's you or me, then they want you to die rather than me. Many

people would be, arguably, better off if their parents (or their children) died. We normally think that this is a good reason to protect them from their 'loved ones', rather than make their continued existence dependent on them.

One further variation of quality control is worth consideration. It is sometimes suggested that since the future existence and size of any community is dependent on the number of fertile females (but only on the existence of one energetic male or a well stocked sperm bank) this partially explains and justifies the widely accepted principle of distribution of scarce life saving resources encapsulated in the slogan 'women and children first'. However, unless a society is in immediate danger of extinction or the number of threatened females is so large as to make this true, it will not be the case in any particular instance that this claim to priority is available to women.<sup>19</sup>

The second part of the slogan 'children first' might involve the claim that children are entitled to priority because they have not had what older people have had, namely the chance to be adults. Consideration of this claim brings us back to the more general problem of the validity of age-related criteria or of those criteria for the distribution of health care resources that use life expectancy at some point.

#### *6. The anti-ageist argument*

We noted earlier that each person is entitled to have his or her life (continued existence) and fundamental interests valued as highly as those of any other in the allocation of community resources that affect life or fundamental interests. Ageist criteria are unjust precisely because they involve counting the lives of the young as more valuable, more worth saving than the lives of the old. This injustice is perhaps best explained as follows. All people who wish to go on living, however uncomfortable their continued existence may be, however many friends and relations they have, however long or short that existence may be expected to be, have something that is of equal value to themselves – the rest of their lives. Each is equally wronged if they are deprived of an equal chance to enjoy the rest of their lives, if their lives are cut needlessly short (that is, if their lives are not prolonged when they want them to

be and when they could be). Whatever the rest of our lives might be expected to be like, so long as we want our lives to continue, then we each suffer the same misfortune, and are wronged in the same way, when that wish is deliberately frustrated by others. This inevitably happens when the resources that we need to keep us alive are deployed elsewhere on grounds that discriminate against us. This argument we can call the 'anti-ageist argument'. It values each individual's life equally irrespective of life expectancy and the amount of life he or she has already enjoyed.

However, the idea that children, for example, are entitled to priority because they have not had what older people have had, namely the chance to be adults, also appeals to a conception of justice or at least to one of fairness. And this idea seems to imply that fairness might animate a pro-ageist argument. For we do surely feel that there is something wrong with a principle that requires us to value at par the claims on life-saving resources made by a 90-year-old and those made by a 20-year-old when we have not the resources to save both. Can these two conflicting views be reconciled?

### 7. *The pro-ageist argument*

This suggests that we have reasons, based on a conception of fairness, to prefer to save the lives of younger people. For such people by definition have not yet had the chance to experience what their older competitors for scarce resources *have already enjoyed*.

There is an immediate problem with the above supposed justification for ageism. It is simply that this rationale for preferring children to adults holds good for any significant age difference. For while the child has not had what older people have had – namely the chance to be an adult, the 30-year-old has not had what the 40-year-old has had, and so on. For fairness can always be appealed to by the younger when their lives are in competition with anyone older than themselves for scarce life saving resources. Suppose places on a dialysis programme are in short supply and a 30-year-old and a 35-year-old are competing for one place. The younger woman can say that the older has already had the chance of five extra years

of life and that it would be unfair further to advantage her at the expense of her younger competitor.

#### *8. Ageism and aid*

Another problem with such a view is that it seems to imply, for example, that when looking at societies from the outside, those with a lower average age have somehow a greater claim on our aid. This might have important consequences in looking at questions concerning aid policy on a global scale. Of course it is true that a society with a low average age might be a good indicator of its need for help; it would imply that people were dying prematurely. However we can imagine a society suffering a disaster which killed off many of its young people (war perhaps), which was consequently left with a high average age but was equally deserving of aid despite the fact that such aid would inevitably benefit the old.

There seems, then, to be something invidious about choosing between lives simply on the grounds of age, whether the rationale be forward looking in terms of life expectancy or backward looking in terms of 'distance run'. There is also of course the problem of the leapfrog effect.

#### *9. The leapfrog effect*

Although a man of 35 can argue that a man of 40 has enjoyed five more years of life and so it would be unfair to prefer him in the competition for scarce resources and thus further advantage an already advantaged individual, there is the leapfrog effect. For if we save the younger man he will be likely to live beyond 40, leapfrogging his now deceased competitor. The latter will now be able to claim (posthumously) that it was unfair to save the younger man because by doing so we have enabled him not only to catch up with, but also surpass, his competitor. So there is something unfair about either method of allocation.

Perhaps the problem can be solved in another way. The old differ from the young not simply (usually) in terms of possessing a diminished life expectancy, but also in having lived a reasonable life, in having had what we might call a 'fair innings'.

### 10. *The fair innings argument*

This argument concentrates on the idea that it cannot be just that someone who has already had more than his or her fair share of life and its delights should be preferred to the younger person who has not been so favoured. This idea involves deciding what a fair share is and adopting that share as a threshold. Thus, on this view, there is some span of years which we consider to constitute a reasonable life – a fair innings – maybe we would consider the traditional ‘three score and ten’ to be such a span. Whatever span we take will in a sense be arbitrary; all that’s important is that it plausibly constitute a reasonable life, such that those who fail to live so long may be considered to have missed out, and those who live longer are regarded as specially fortunate.

The fair innings argument enjoins us to give priority in resource allocation to those who need such resources in order to have a chance of achieving a fair innings, and only when these claims have been satisfied to help those who have already had their fair share of life.

To be sure, even those who have had a fair innings are wronged when their lives are cut prematurely short, when resources which could further prolong their lives are allocated elsewhere. But they are not wronged when they lose out in an unavoidable and just distribution of scarce resources. The fair innings argument treats people as equals in that it recognises that each has an equal right to life and an equal interest in living long enough to have a reasonable life. It avoids the double jeopardy problem of QALYs and other measures which use simple life expectancy as a criterion, and it recognises what is perhaps a truth about existence: that whereas it is always a misfortune to die when one wants to go on living, it is not a tragedy to die in old age.

However this may be, the fair innings argument can, like QALYs be dangerous in that it encourages the idea that there is *nothing wrong* with abandoning the old to their fate and concentrating on those who have not had a fair innings. We should remember that the fair innings argument is only plausible in extreme emergency when hard choices have to be made. I will say something about just what constitutes

such extreme emergency when we come to consider 'just distribution' in the final section of this chapter.

### *11. Conclusion*

The only way to deal with individuals in a way which treats them as equals when resources are scarce, is to allocate those resources in a way which exhibits no preference. To discriminate between people on the grounds of quality of life, or QALY, or life expectancy, or on the grounds that they have dependants or friends, is as vicious and unwarranted as it would be to discriminate on the grounds of race or gender.

So, the problem of choosing how to allocate scarce resources is simple. And by that of course I mean 'theoretically simple', not that the decisions will be easy to make or that it will be anything but agonisingly difficult actually to determine, however justly, who should live and who should die. Life saving resources should simply be allocated in ways which do not violate the individuals' entitlement to be treated as the equal of any other individual in the society. And that means their entitlement to have their interests and desires weighed at the *same value* as those of anyone else. The QALY and the other bases of preference we have considered are irrelevant.

If health professionals are forced by the scarcity of resources to choose, they should avoid unjust discrimination. But how are they to do this?

### **Just distribution**

If there were a satisfactory principle or theory of just distribution now would be the time to recommend its use.<sup>20</sup> Unfortunately there is not a completely satisfactory principle available. However we can come close to justice in many cases by using a very simple and traditional remedy. The task is to allocate resources between competing claimants in a way that does not violate the individual's entitlement to be treated as the equal of any other individual – and that means his or her entitlement to have his or her fundamental interests and desires weighed at the same value as those of anyone else. The QALY and other quality of life criteria are vicious and irrelevant, as are

considerations based on life expectancy or on 'life years' generated by the proposed treatment. If health professionals are forced by the scarcity of resources to choose, not *whether* to treat but *who* to treat, they must avoid any method that amounts to unjust discrimination. One way of doing this which holds good for a large number of cases is to draw lots.

There may also be good practical as well as moral reasons to do this and to publicise what is being done. Firstly drawing lots does not involve the corrupt and corrupting deception that occurs when it is alleged that particular patients cannot be helped medically. They can if resources are not deployed elsewhere. Secondly, if people are uncomfortable with the apparent arbitrariness of drawing lots, they have a motive for trying to ensure that more resources are available for health care so that such stark choices are minimised. But perhaps most important, drawing lots or something like it, values each person at one and none at more than one. While this may not be efficient, it is a policy that does at least embody the values most people believe do and should underlie the health service as a whole. These are, as we have seen, the belief that the life and health of each person matters, and matters as much as that of anyone else, and that each person is entitled to equal concern and respect, both in the way resources are distributed and in the way they are treated generally by health care professionals. Such a method of distribution is, as I have indicated, not without its limitations. To see the extent of these we must bear in mind the distinction, already noted, between life saving and life enhancing procedures.

### *1. How scarce are resources?*

While it is true that resources available for medical care will always be limited, it is far from clear that this applies to the resources necessary to save those in real and immediate danger of death. If the fair innings argument is invoked, giving priority to those endangered individuals whose death would mean their missing out on a reasonable lifespan, then it is very likely that in most cases there are sufficient resources available to treat all those in immediate danger of death.<sup>21</sup> Of course to do this in the United Kingdom, and probably also in many other

industrialised societies, we would need to allocate a greater proportion of the national budget to health care.

### *2. Defensive medicine*

People within health care are too often forced to consider simply the question of the best way of allocating the *health care budget*, and consequently are forced to compete with each other for resources. Where lives are at stake, however, the issue is a moral issue which faces the whole community and, in such circumstances, calls for a fundamental reappraisal of priorities. The question should therefore be posed in terms, not of the health care budget alone, but of the *national budget*.<sup>22</sup> If this is done it will be clearer that it is simply not true that the resources necessary to save the lives of citizens are not available. Since the citizens in question are in real and present danger of death, the issue of the allocation of resources to life saving is naturally one of, among other things, national defence. Clearly, then, health professionals who require additional resources simply to save the lives of citizens have a prior and priority claim on the defence budget.

QALYs encourage the idea that the task for health economics is to find more efficient ways of doing the wrong thing – in this case sacrificing the lives of patients who could be saved. All people concerned with health care should have as their priority defensive medicine: defending their patients against unjust and lethal policies, and guarding themselves against devices that tend to disguise the immorality of what they are asked to do.

### *3. Priority in life saving*

It is implausible to suppose that we do not have sufficient resources to save the lives of all those in immediate mortal danger. It should be only in exceptional circumstances – unforeseen and massive disasters for example – that we cannot achieve this. However, in such circumstances our first duty is to try to save the maximum number of lives possible. This is because, since each person's life is valuable, and since we are committed to treating each person with the same concern and

respect, we must preserve the lives of as many individuals as we can. To fail to do so would be to value at zero the lives and fundamental interests of those extra people we could, but do not, save. Where we cannot save all, we should select those who are not to be saved in a way that shows no unjust preference – by lot for example.<sup>23</sup> And this principle should apply to all people equally. The fair innings argument should only be invoked as a counsel of despair; when it is quite clear that unless it is invoked, the lives of those below the fair innings threshold will have to be sacrificed to preserve the lives of those who have already had a fair innings.

We should be very clear that the obligation to save as many lives as possible is *not the obligation to save as many lives as we can cheaply or economically save*. And, surely, the problems arising out of overspending a limited health care budget do not amount to a disaster which forces us to choose between lives.

There are multifarious examples of what I have in mind here and just a couple must suffice to illustrate the point. Suppose, as is often the case, providing health care in one region of a country<sup>24</sup> is more expensive than doing so in another, or saving the lives of people with particular conditions is radically more expensive than other life saving procedures, and a given health care budget won't run to the saving of all. Then any formula employed to choose priorities should do just that. Instead of attempting to measure the value of people's lives and select which are worth saving, any rubric for resource allocation should *examine the national budget afresh* to see whether there are any headings of expenditure more important to the community than rescuing citizens in mortal danger. For only if all other claims on funding are plausibly more important is it true that resources for life saving are limited.

#### 4. Priority in life enhancement

Only when all demands on resources for life saving have been met should life enhancement be undertaken. And in by far the larger part of the health service, resources will be limited. The situation is immensely complex. Many routine procedures and treatments are not immediately life saving, but their neglect or postponement might be life endangering. And this would hold

true for so called 'first line' medicine where patients are assessed. So, to have a rational and just distribution of health care resources, a fully functioning and comprehensive health service is required. But within such a service it is certainly possible to discriminate between life saving and life enhancing procedures, and to make decisions about priorities.

The question now arises as to what is a morally defensible method of distributing scarce resources between the multifarious claims to health care.

I shall not attempt to solve this problem, for my purpose has been to concentrate on the allocation of life saving resources and on the defects of one particular approach to this question. However, the argument so far indicates legitimate and illegitimate approaches to a solution.

Priority setting in health care generally will have to take account of levels of pain, distress, mobility and the other sorts of factors measured by the Rosser and other scales. So, of course, quality of life considerations are relevant to the assessment of life enhancing measures – that is all they have to offer. Priority setting will also have to take account of various ways in which systematic disadvantage can be built in to any society. (I'm thinking here of the sorts of inequalities in health care highlighted by the Black report<sup>25</sup> for the United Kingdom and doubtless very evident in other societies as well.)

It is clear that QALY-type measures of efficiency will not help here either. Many of the reasons for this we have already noted. It is worth reminding ourselves, however, that any measures which depend on life expectancy as a measure of success cannot hope to deal justly with claims that are strong simply because of systematic and accumulated neglect. Someone who has suffered years of remediable pain and immobility may be entitled to priority on that account alone even though, since he or she is old, the prognosis in life year terms is not good. Certainly his or her claim to fair consideration should not be automatically ruled out by something as insensitive as the QALY.

A recent BBC television programme<sup>26</sup> calculated that if a health authority had £200,000 to spend it would get 10 QALYs from dialysis of kidney patients, 266 QALYs from hip replacement operations or 1197 QALYs from anti-smoking

propaganda. While this information is undoubtedly useful, and while advice to stop smoking is an important part of health care, we should be wary of a formula which seems to dictate that such a health authority would use its resources most efficiently if it abandoned hip replacements and dialysis in favour of advice to stop smoking.

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#### Notes and references

- 1 If this claim seems to be in need of further justification see John Harris. *The value of life: an introduction to medical ethics*. London, Routledge and Kegan Paul, 1985, chapter 2.
- 2 See the excellent discussion of the recent history of this line of thought in *Office of Health Economics. The measurement of health*. London, Office of Health Economics, 1985.
- 3 Alan Williams. Economics of coronary artery bypass grafting. *British Medical Journal*, 291, pages 326-329, 1985; and his contribution 'The value of QALYs' to the Centre eight - In search of efficiency. *Health and Social Service Journal*, 18, July 1985. These are by no means the first such attempts. Again see *The measurement of health* (see 2 above).
- 4 See Alan Williams. The value of QALYs. *Health and Social Service Journal*, July 1985.
- 5 I mention this in case anyone should think that it is only medical scientists who do medical research.
- 6 See 4 above, page 3.
- 7 See 2 above, page 16.
- 8 See 4 above, page 5; and as clearly outlined in the quotation from page 3 of the same work.
- 9 I will assume this can be described as 'true' for the sake of argument.

- 10 I am indebted to Dr S G Potts for pointing out to me some of these statistics and for other helpful comments.
- 11 See John Rawls. *A theory of justice*. Cambridge, Mass, Harvard University Press, 1971.
- 12 See Derek Parfit. *Innumerate ethics*. *Philosophy and Public Affairs*, 7, 4, 1978. Parfit's arguments provide a detailed defence of the principle that each is to count for one.
- 13 Ronald Dworkin. *Taking rights seriously*. London, Duckworth, 1977, page 227.
- 14 I do not, of course, mean to imply that there are such things as rights, merely that our use of the language of rights captures the special importance we attach to certain freedoms and protections. The term 'civil rights' is used here as a 'term of art' referring to those freedoms and protections that are customarily classed as 'civil rights'.
- 15 There are other good reasons for discounting such considerations as irrelevant. See 1 above, chapter 5.
- 16 For an account of the Rosser scales see 2 above; and R M Rosser. *A history of the development of health indicators*. In: G Teeling Smith (ed). *Measuring the social benefits of medicine*. London, Office of Health Economics, 1984.
- 17 Both these dimensions are considered at greater length in *The value of life* (see 1 above), chapter 5.
- 18 Jonathan Glover. *Causing death and saving lives*. Harmondsworth, Penguin, 1977, page 222.
- 19 Any men likely to be adversely affected by such a claim would be entitled to see certificates of fertility and to cast iron guarantees that the surviving women would (or would be forced to) reproduce to the value of the lives sacrificed for the sake of their reproductive utility. Not a condition likely to recommend itself to many women.
- 20 For an interesting attempt to fill this gap see Ronald Dworkin. *What is quality?* *Philosophy and Public Affairs*, 10, 4 and 5, 1981.
- 21 This will certainly be true for most industrialised societies and probably for the world as a whole if richer countries recognise their obligations to people whose lives they could save. For the arguments to this end see Peter Singer. *Famine, affluence and morality*. *Philosophy and Public Affairs*, 1, 1972; and John

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Harris. *Violence and responsibility*. London, Routledge and Kegan Paul, 1980.

22 And, of course, the international budget. See 21 above.

23 Or any other such method.

24 Or of the world of course. The obligation would then be seen in terms of providing resources for aid on an international scale rather than on increases in the health budget of a particular country.

25 See Peter Townsend and Nick Davidson (eds). *Inequalities in health: the Black report*. Harmondsworth, Penguin, 1982.

26 *The Heart of the Matter*. BBC1, October 1986.

## CONTEMPORARY ISSUES IN FAMILY PLANNING

John McEwan

### Introduction

Family planning is a subject with complex and indefinite boundaries. It describes a form of human behaviour which entails placing intellectual order on natural reproductive contingency. This phrase is frequently used to describe an area of clinical practice which, in itself, is ill-defined. Sometimes it means just reversible contraception; at other times it may include sterilisation, counselling for psychosexual problems, or even induced abortion. Most clinicians would suggest that, in practice, it includes counselling and advice on infertility or delayed fertility, but most people generally think of family planning merely as preventing pregnancy. It may also refer to a socio-political programme, usually having governmental backing. There are many pseudonyms or euphemisms: birth control, planned parenthood, fertility control, conception control, family limitation. Since family planning cannot take place without an intention being formed, 'planning' is not an inappropriate word to use. The subject is studied by a variety of academics and other professionals: doctors, nurses, counsellors, social workers, reproductive physiologists, endocrinologists, gynaecologists, andrologists or urologists, cytopathologists, semenologists, demographers, statisticians, sociologists, and social anthropologists.

Since human beings and their reproduction take centre stage for this wide audience, ethics and the law are vitally intermingled. The spectrum of political philosophies concerned with family planning is wide, from legalised coercion at one

extreme to individual freedom of choice at the other. On the users will impinge a variety of forces: economics, nutrition, health, social welfare, sexual mores, the desire for a family of a particular size and combination of genders, and perceptions of parental capability, to name only some of the influences.

This chapter highlights some of the ethical forces at work in a narrow part of the field of family planning, chiefly the doctor-client relationship, looking especially at the attitudes of each side and relating the influence of the professional against the needs of the consumer. These sections will emphasise mainly the provision of contraceptive services in a clinical setting, rather than consider fully the wider areas of abortion, sterilisation and assisted reproduction. It seems relevant, at the onset, to give a brief outline of the medical features of current contraceptive practices, looking at effectiveness and to some extent morbid complications. Following this overview, a special comment is made about so-called 'natural' methods. Out of all this arises the requirement on the clinical prescriber to balance, on the one hand, the needs of users and, on the other, to limit the chance of pregnancy against the chance of an adverse event. The equation is then placed in the setting of background values on abortion and sterilisation which hang like shadows behind the interaction between client and adviser.

From these considerations come questions of consent to clinical interventions, an area in which people may feel a double injury in their application – one to their general well-being, another to their reproductive potential. Then comes a more detailed look at how doctors and patients relate in these no-disease situations, in which the need is emphasised for women, the potentially pregnant gender, to have the freedom to relate to women practitioners if they wish.

Finally some very brief comments are included on the social influences contributing to people's decisions about family size and the relation these bear to the political perceptions of population growth as a problem for the world. So the following sections form a somewhat idiosyncratic group of topics which seem to have some logical connection. By no means can they claim to be the last word on the ethical and legal aspects of family planning.

### Medical aspects of contraceptive methods

Much of the attention given to modern contraceptive methods arises from their startling efficiency. For the first time in history it has been possible for the great majority of couples to plan their families precisely without resorting to infanticide, abortion or abstinence. All these methods were used in the past and all, in varying degrees across the different cultures, were unacceptable. Contraception, as opposed simply to birth control – or child control – has come into its own. This has only happened by making fairly serious incursions into the delicately balanced physiological process of reproduction. With this degree of biological intervention, side effects and adverse reactions inevitably arise, although serious harm may only come to a small proportion of users. There was a time when any drug or device applied to healthy people would have been rejected out of hand by doctors if there had been a suspicion that, in a small number of individuals, serious disease or death might occur as a result of using it. Professional and popular belief has moderated since those days. This largely happened after the alarmist discussion of population pressure started in the 1950s in the United Kingdom by Julian Huxley. There was also a growing realisation by clinical and social professionals that excessive or unwanted child-bearing can itself have morbid and mortal effects on mothers. While scientific medicine tries constantly to improve the safety of the agents used, there still remains the need to consider contraceptive methods as having benefits and risks and these have to be balanced by clinicians and users. The dangers also dictate that the most effective methods are only available in this country by medical prescription.

Before continuing the wider discussion, it is relevant to consider the medical features of current methods of contraception which the clinician must try to explain to the person or couple he is advising. (Doctors in family planning are more often female than male but for clarity the male pronoun will be used in this chapter to denote either sex.)

Table 1 (page 132) gives the overall pattern of contraceptive effectiveness of different methods, taken from the *DHSS Handbook of Contraceptive Practice* (revised 1984). There are

differences in meaning and implication in the ways in which effectiveness is expressed. This table is therefore usefully indefinite. The usual measure is of 'accidental pregnancies per 100 women-years'. If a well-organised and disciplined clinical trial is under way with hundreds, or thousands, of fully obedient subjects carrying out the instructions faithfully, the investigator may end up with an 'ideal' figure for any given method. This is known as the 'method failure rate' and is said to be an inherent property of the method. As any outsider can guess, the groups studied and the individuals within them vary in fecundity, in coital behaviour and in compliance. Investigators' standards of trial organisation and recording also vary. Further, the 'ideal' figure may vary, according to the length of time the method has been used, for example. Finally, analysis of the observations can be quite complex in arriving at this measure of 'effectiveness' and its validity may always be questionable on statistical grounds.

The ideal of 'method failure rate' may therefore have only oblique relevance to clinical practice. A method may be perceived as unpleasant, or experienced as painful, or for some couples it may interfere in the enjoyment of love-making. Any method producing any of these effects is unlikely to be used correctly on a wide scale. These factors bear on what is described as the 'acceptability' of methods and this may have an overriding influence on effectiveness. One feature which variably but noticeably affects the acceptability of the more invasive medical methods is the pot-pourri of opinions expressed in the media from time to time. These are usually about adverse effects and the negative features which are frequently presented to the public in the most sensational way.

Table 1 then represents a reasonable approximation of the effectiveness of the methods in terms of their everyday use. This is the benefit side: what about the risks? With regard to death, disease and disability, there has been some variation in the extent to which studies have been undertaken concerning the different methods. For example, the combined oestrogen-progestogen pill, the commonest type of hormonal contraceptive (usually called 'the pill'), has been extensively studied in prospective surveys over many years in the United Kingdom and in the United States. These studies have sometimes been

Table 1 Relative effectiveness of contraceptive methods

Withdrawal	Depends very much on the users.
Rhythm, 'natural' methods or periodic abstinence	Overall effectiveness is poor but could be made much more precise by accurately detecting ovulation.
Condom, vaginal barriers, progestogen only pill	Reasonably reliable if used correctly; pregnancy rate about 2-3 per 100 woman-years.
Intrauterine device	Less dependent on the user; pregnancy rate about 1.5 to 3.0 per 100 woman-years.
Comb ned pill, depot injection	Highly reliable if used correctly; pregnancy rate about 0.1 to 0.4 per 100 woman-years.
Female sterilisation, vasectomy	Highly effective with overall failure rates of less than 0.5%.
Post-coital contraception	(For emergencies only) Hormonal and IUD methods each have a failure rate of about 1%.

Source: Modified from *Handbook of Contraceptive Practice*, DHSS, revised 1984.

over a complete range of adversity, as in the oral contraception study by the Royal College of General Practitioners<sup>1</sup>, or over a limited but important range of disease, as in the cancer and steroid hormones study<sup>2</sup> and in the Boston stroke study<sup>3</sup>, both of which were completed in the United States. The adverse effects of intrauterine devices (IUDs) have not been so comprehensively followed up: evidence has come from retrospective surveys of certain individual disorders believed to be connected with IUD use; for example, tubal infertility<sup>4</sup> and ectopic pregnancy.<sup>5</sup> With other hormonal methods, mostly those using progestogen without added oestrogen, there is relatively little information associated with their adverse effects, although there is now quite good information on their contraceptive effectiveness.<sup>6</sup>

Table 2 (page 134) shows the chief disorders associated with the use of the more invasive contraceptive methods. When a disastrous event occurs in a small minority of a population all using the same drug, it is always difficult to understand why the disaster should have happened to each one of those individuals. Is it another expression of 'normal distribution'? Or is there some susceptibility in that person, another 'risk factor', which has combined with the drug to kill or maim? In the case of the combined oral contraceptive pill (COC), a great deal of work has been done on risk factors and in this country prescribing policy has consequently been changed to minimise the frequency of adverse effects. Additionally, the composition of the COC pill has been changed, once the component causing an adverse effect was identified.<sup>7</sup> In many ways this is a satisfactory story. Unfortunately, it cannot be said, even after all this modification, that all risks have for certain been removed. Table 3 (page 136) illustrates how this modification has taken place.

In practice, it is unlikely to be possible in the future to obtain evidence of any value in large prospective studies of COC pill users. The morbidity incidence is low and to find a statistically significant difference with a control group large cohorts of users and controls would be required and they would have to be observed over many years. Also, in settling such questions as the risk of cancer in pill takers, the latent period of such an effect may be prolonged, say 15 years or more, and it is extremely difficult to maintain good logistic control of a large cohort in such a follow-up period. Recent studies looking at breast cancer risks have used retrospective methods, sampling women having breast cancer at an unusually early age and comparing pill use with that of a matched control group.<sup>8,9</sup>

Regarding cardiovascular risks in COC pill users (for example stroke and coronary heart attack) there has been an emphasis recently on changes in biochemical variables in users compared with controls. The effect on the lowering of high density lipoprotein-cholesterol has been studied. Naturally this method of evaluation raises the question of the association between changes in the variable and morbidity and also whether the correct substance – or correct fraction of such a substance – is being estimated. Fallacies creep in very easily and sometimes these appear in the promotional literature.

Table 2 Side effects associated with combined oral contraceptive pills

<i>Major adverse effects</i>	<i>Discomforts</i>	<i>Effects of uncertain association</i>
Deep vein thrombosis	Breakthrough bleeding	Eczema and related skin conditions
Pulmonary embolism	Absence of withdrawal bleeding	Increased susceptibility to some infections
Myocardial infarction	Loss of libido	Post-pill amenorrhoea (anovulation)
Cerebral thrombosis	Weight gain	Cervical neoplasia
Other thrombotic events	Failure of vaginal lubrication	Breast cancer
Cerebral haemorrhage	Recurrent vaginal candidosis	
Hypertension	Discharge associated with cervical ectopy ('erosion')	
Severe depression	Facial hirsutes	
Severe migraine/ headache	Ankle oedema	
Gall bladder disease*	Breast pains	
Jaundice	Increase in acne	
Exacerbation of diabetes	Anxiety and mild depression	
Exacerbation of epilepsy	Leg pains	
Hepatic tumours	Persisting nausea	
	Chloasma (facial pigmentation)	
	Abdominal bloating	
	Irritation from contact lenses	
	Galactorrhoea (inappropriate lactation)	

\* Gall bladder disease occurs earlier in women on the combined pill who are predisposed to this condition.

Source: Modified from *Handbook of Contraceptive Practice*, DHSS, revised 1984.

The process of looking for unwanted actions of the combined pill has revealed some cases where the combined pill can improve the expectation of health of its users. The RCGP study revealed that the frequency of rheumatoid arthritis was less in pill takers<sup>10</sup> and another study revealed that there was a slightly lower risk of disorders of the thyroid gland.<sup>11</sup> Studies on breast disease showed a lower incidence of the biopsy of breast tumours with benign findings.<sup>12</sup> But perhaps the most striking effects related to two important long-term protections against cancer: the incidence of ovarian cancer in pill takers is reduced to a third of the incidence in non-users; and that of endometrial cancer is reduced to 40 per cent of the risk in non-users.<sup>13</sup> Also the protective effects last for many years after cessation of pill use. These beneficial and important effects on health are sometimes put together with the known adverse effects to be weighed in the balance of a 'risk-benefit equation'. The implication is that women should be content with the risks since they reap the benefits. This seems a simple-minded approach to the problem for the intending user. Firstly, the woman's feelings are likely to be more centred upon the adverse effects whatever the statisticians say; and secondly, if you die from a stroke or cervical cancer it is no consolation to be informed that you will not be dying from ovarian cancer. The two probability chances are not equivalent quantities to be added or subtracted: the main consolation from the benefits may be for the prescriber.

Much attention has been centred on the popularity of the combined pill as a convenient and effective contraceptive and because it became clear, 20 years ago, that there was a definite mortality associated with its use.<sup>14</sup> In comparison, for example, it is not so clear that there is a mortality risk associated with the use of intrauterine devices. It is known, however, that seriously morbid conditions can arise in users which, in turn, may lead to death if treatment is not effective or the condition is not correctly diagnosed early enough. Perforation of the uterus can occur at the time of insertion. This is a potentially hazardous situation with a foreign body in the peritoneal cavity but is fortunately a rare occurrence, especially if the insertion procedure is carried out correctly.

Most hazards attributable to IUDs are related to disorders of

Table 3 Approximate representation of changes in the design of combined oral contraceptives over 25 years

	<i>Daily oestrogen dose equivalent to micrograms of ethinyloestradiol</i>	<i>Daily progestogen dose equivalent to micrograms of norethisterone</i>	<i>Problems</i>
1961-1969	50 to 150	1000 to 4000	Thrombo-embolism
1970-1975	30 to 50	500 to 3000	Coronary attacks and strokes
1976-1986	30 to 35	458 to 1250	Diminished cycle control and conception control

Explanatory notes: 1 Figures selected from combined pills commonly prescribed.

2 Norethisterone dose assumed to be five times the equivalent dose of levonorgestrel.

3 Daily dose of each component averaged per packet of 21 pills.

the fallopian tubes:<sup>15</sup> ectopic pregnancy, a highly dangerous condition which can cause sudden heavy internal bleeding; tubal infertility, associated with the aftermath of infection; and long-term or recurrent infection in the pelvic organs. If a pregnancy occurs with an IUD still inside the uterus there is a risk of infection in the pregnancy, which is another dangerous but uncommon condition. Here again risk factors arise, as with the COC pill. Research studies have shown that women who have never been pregnant are much more likely to develop infection due to an IUD than those who have borne at least one child.<sup>16</sup> Selective prescribing can therefore minimise the risks. Lifestyle is also a factor in the infection risk and it seems likely that the presence of an IUD may make the effect of a sexually transmitted infection more serious for the woman. If either one of a couple has (or has had) other sexual partners they would be well advised to use condoms as well as their established contraceptive method to minimise the risk of transferring infection. This practice is becoming increasingly established as a precaution against the transmission of the AIDS virus.

Barrier methods show little in the way of associated morbidity risks. There is an association between use of the diaphragm and urinary tract symptoms or infections<sup>17</sup>, but this can be avoided by appropriate advice and treatment, perhaps using a different type of vaginal or cervical cap in those who are susceptible. Barrier contraceptives are widely believed to reduce the risk of sexual transmission of infections and it is an added bonus that some modern spermicides are active against viruses.<sup>18</sup>

One further method is available which is little used in this country but has potential for an important place in the range of contraceptives anywhere in the world. This is the depot (or reservoir) injection, given deeply into muscle, of a large dose of progestogen on its own in a form which is only made available to the body over a prolonged interval of time. Injections of depo-medroxyprogesterone acetate as poorly soluble fine crystals every 12 weeks, or of a norethisterone ester (oenanthate) in a solution of oil every eight weeks, give a high effectiveness of contraceptive protection of the same order as the COC pill.<sup>19</sup> They exploit the same activities as progestogen-only pills, but as the initial dose is relatively high, giving higher

blood levels, ovulation is also inhibited most of the time. Unfortunately, uterine bleeding patterns may become very irregular or bleeding may become absent altogether, but there is no report of morbidity of the same kind as with the COC pill, although high density lipoprotein - cholesterol is reduced in users of both these preparations. It is only relatively recently, in 1984, that depo-medroxyprogesterone acetate was licensed for long-term use in Britain and at the time of writing norethisterone oenanthate is only to be promoted for use over brief durations.

### Effectiveness, morbidity and acceptability

The background so far described leads to some hard choices for the potential user of contraceptives. The aim is to provide risk-free and trouble-free protection against pregnancy in the face of continuing, satisfying and enjoyable sexual activity. Some have questioned whether this is possible. The 'engineering' approach to life's problems in the western world leads us to believe that, with appropriate scientific development and application, life can be enhanced indefinitely. The story of contraception over the last 30 years has not succeeded in fulfilling the implied promise. It is more an illustration that advances are accompanied by costs. Consumers are more aware now of these costs and there is a current mistrust of the professionals, the 'engineers'. The fear is that they may not always be sufficiently active in pursuing the consumers' best interests. In particular, doctors and nurses like apparently simple solutions - for example, stitching a wound or prescribing antibiotics for infections - which enable them to move on easily to the next problem. In contraceptive clinical care, there is a realisation that more is needed than reaching for the prescription pad. Successful family planning implies a persistent use of various methods in a woman's reproductive life of some 30 years, apart from the two or three times when she wishes to become pregnant. For this degree of perseverance, a state of conscious self-discipline is needed which can only be attained with full and careful discussion and with an explanation of the methods available and their characteristics by the clinical expert (nurse or doctor). Trust and confidence, and

thus a good relationship, must be built up by giving time and attention. Part of the requirement is to preserve the autonomy of the consumer, with the woman and preferably her partner involved in making decisions to meet their changing contraceptive needs over the years of potential fecundity. Effective use of a method depends not only upon its 'ideal' or theoretical effectiveness, but a great deal upon the acceptability of using it for the couples concerned. For example, many women become worried by unscheduled vaginal bleeding out of line with the menstrual rhythm to which they are accustomed. Hormonal (pill) methods and IUDs cause this from time to time. A great deal of anxiety and loss of confidence may occur unless this feature has been previously explained. For many women world-wide, bleeding between periods means uterine disease, probably cancer.

One of the most taxing issues for the clinician to deal with is the balance of risks and benefits. Not all consumers are sufficiently *au fait* with horse-racing and gambling to appreciate the stated probability of an event in practical terms. If a doctor says the risk of a stroke is 1 in 2000, the reply is frequently: 'but that'll be me, doctor!' How is this to be weighed against the statement that pregnancy only occurs, if the method is correctly used, in one in every 300 women using the method each year? It is equally hard for the consumer to imagine having an unplanned pregnancy. The possibility seems remote, perhaps unimaginable in any detailed way. The reality of facing up to deciding whether to have the child or an abortion, if that were available, has not been reached and advance prediction of her feelings is too difficult. A woman may therefore settle on a method which is not ideally suited to meet her need for contraceptive security, for example, a method where the accidental pregnancy rate is too high. Balanced against the effectiveness factor there may be a fear of the effect of 'taking hormones' on her body chemistry, her sexuality, or her future health. The clinician adviser may be relatively powerless to combat by rational and sympathetic arguments the influence of media scare stories and a rapidly taken sample of peer group opinions. Added to these elements is mistrust of the professional who may be seen by the consumer as not telling the whole truth; who may even be perceived as trying to

pursue community rather than individual aims (such as preventing unwanted pregnancies among lower socio-economic groups or black people) and therefore using some kind of social engineering. These barriers need to be met and surmounted in the clinician-client relationship if there is to be trust and effective communication.

Considerable mistrust of orthodox medicine has centred around the prescribing of depot injections of progestogens, in particular depo-medroxyprogesterone acetate.<sup>20</sup> Much of this mistrust has arisen through a disastrously ill-applied use of this drug, some years ago now, in certain maternity and gynaecological units. Women who had just had babies, or those who had induced abortions, were given the injections routinely. It was known that the preparation was medically safe, did not interfere with lactation or with the health or well-being of breast-fed babies. There was, however, the risk of irregular and sometimes very heavy uterine bleeding at the time when oestrogen levels fall, as they do in some women after the end of pregnancy. And in a minority of women there would be a prolonged duration of no periods at all, amenorrhoea, often lasting for six to twelve months and, in a small proportion, up to two years after the last dose of the drug.

The disastrous effect lay in the failure of hospital staff on many occasions to explain exactly what they were doing and why, and what the effects of the injection would be. Even if some explanations were given, there was little or no negotiation or encouragement for the woman to come to a decision autonomously. It was given as a routine, like anti-D, rubella inoculation and a packet of iron tablets. Furthermore this was considered good medical practice by some authorities. While it is appreciated that many such units were very busy and understaffed, perhaps even short of staff who understood contraceptives and their application, one still should not treat fertility in people as if they were a herd of farmyard animals, any more than one should consign the elderly to the knacker's yard. This is a kind of thoroughly unsatisfactory result arising from attempts at social engineering in clinical medicine. It is both ineffective in the long-term and ethically unacceptable. There was a vigorous reaction of protest from the suffering public and, unfortunately, the calumny centred on the drug

instead of on the prescribers. 'Depo-Provera' was only approved finally for long-term use after a great deal of political oscillation following the quite rational recommendation of the Committee on Safety of Medicines.

The stigma is a great pity as the drug is a most successful and, for many women, comfortable contraceptive which is much underused. Many of those active in struggling for women's rights to be recognised still hold the view that it is some kind of vicious poison. This salutary story demonstrates the importance of prescribing for each individual in family planning and the need for the medical aspects to be openly discussed with potential users.

Turning to the media (newspapers, TV, radio, magazines and the like) their information is evanescent. A story may be sensational for a day and then be forgotten. Items connected with fertility and hence with sexuality can easily be made sufficiently dramatic for journalists to find the attention of a wide audience. It follows that articles in the medical press relating to fertility control methods, particularly if it has been found that some damage or ill-health can be caused, are seized upon quite eagerly by the media and attempts made, often quite unsuccessfully, to retail the findings to the general public. The lack of success lies in difficulties in the accurate representation of technical detail into everyday language, but it seems that if the story is made dramatic enough it will appear in some kind of an account, however garbled. The effect on the consumer is frequently very serious. A method, such as the COC pill, which has been perceived as safe, secure and comfortable to use, is suddenly seen as a prominent danger. Understandably, many will be impressed by the popular stories and will instantly stop using the method. Each episode of this kind in the history of the more modern, intrusive contraceptive methods is followed, a few months later, by an increase in abortion requests. Overall, in considering the combined pill as a prototype for this process, public confidence is undermined and there is a steady decline in use. The COC pill is a very safe form of medication for those with no other risk factors for a particular condition (for example, the added risk of smoking to possible coronary heart disease). The pill does little on its own to harm its users.

To a great extent, the professionals are at fault for not providing sound and comprehensive information to the media when there is a dramatic scare. Problems lie in the speed of reaction when reports of adverse effects are published in the medical journals. The public media react more quickly than the relevant part of the medical establishment. There are signs, however, that there is an improvement in this direction. Chairmen of the Committee on Safety of Medicines have spoken out with some courage, at an early stage in the debate, with statements intended to counteract sensationalism. But it takes time for opinions from groups of experts to be considered. There is the added factor that the consumer may not entirely trust the establishment medical figures. She will, however, be more likely to trust the doctor or nurse with whom she has a well-developed and trusting clinical relationship.

#### The effect of attitudes to abortion on the contraceptive consultation

Induced abortion is a contentious issue. The act is against the so-called 'Hippocratic' tradition. It is also against the religious beliefs of a large proportion of the world's population. Officially permitted induced abortion is, arguably, one of the most outstandingly successful measures in preventive health care that exists.<sup>21</sup> It is not the purpose of this section to pursue these points, but to look at attitudes to abortion in relation to the choice of contraceptive methods and the advice given by clinicians in that context.

The important point to be grasped by any contraceptive adviser is that the views of the user on abortion are highly relevant to the choice of method. Statisticians have repeatedly demonstrated (for example, the late Christopher Tietze of the Population Council<sup>22</sup>) that the method of fertility control that is safest for a woman's health is the use of a vaginal barrier method with spermicide, backed up in case of failure by early-gestation induced abortion under local anaesthesia. There is virtually no morbidity from this contraceptive method. Early pregnancy termination is very free of complications when undertaken by competent hands in medically safe surroundings. Anaesthetic risks are avoided by the administration of

local anaesthetic. Some problems arise; for example, many gynaecologists find that local anaesthesia does not adequately relieve operative pain. The infection risk to the tubes is not entirely obviated by operation in early gestation, especially if the cervix is infected. Abortion is not freely available on request in this country under the law, so it can be said that it might not be available when required under this method of fertility control. Finally, of course, a vaginal barrier may not be acceptable to a woman or her partner and, more particularly, having an abortion may be quite unacceptable.

There are religious grounds for not accepting abortion; for instance, being a Roman Catholic, a member of some other Christian denomination, an Orthodox Jew or a Buddhist. However, quite apart from religious beliefs, some couples would not countenance an abortion, unless perhaps there was some serious medical reason, and would certainly not include it as part of a contraceptive strategy. Therefore, if a woman chooses a contraceptive method with a palpable failure rate she must be asked at an early stage whether the possible need for abortion has been considered. It may be added that the consequences of intercourse with a man who would not be acceptable as a long-term partner should also be carefully considered if a child might be the outcome of the relationship. For if pregnancy would be an absolute disaster, it becomes essential to consider only the most highly effective forms of contraception, probably entailing the combined pill or the depot injection of progestogen. It is unrealistic to think otherwise, because of the risks of failure inherent in other methods.

Attitudes to abortion must therefore profoundly effect contraceptive choice. This is in a country where the law is fairly liberal. In those countries where legal abortion is not available (and illegal abortion is highly dangerous) then these considerations must be applied to everyone who wishes to avoid conception.

#### The effect of attitudes to sterilisation on the contraceptive consultation

Over the last 30 years in Britain, attitudes to having a family have completely changed. In 1957, many pregnancies, probably

over half, occurred by chance with no particular intention on the side of the parents. A family arrived therefore without necessarily being predetermined as to size, or at what stage in a couple's fertile life the children were born. The effect on the parents varied from resignation to agony, so that the promotion of family planning seemed an urgent priority in family health care. The prevalence of gynaecological morbidity reflected all the ills from excessive parity, successive births too closely spaced and the dire effects of illegal 'back-street' abortions. It was Dugald Baird of Aberdeen who cut a preventive swathe through this forest of illness in his pioneering studies on a liberal policy of induced abortion, contraception and sterilisation.<sup>23</sup>

Today public attitudes to child-bearing have radically changed. Young couples decide at an early stage how many children they will have (either two or three, rarely four), when they will have them (usually when they have some savings and the woman can give up earning for a time), and when they will reach the stage of being certain that they want no more. In this context, and given the previous comments on attitudes to the most effective contraceptive methods, sterilisation has become very popular. Probably a third of all couples now use female sterilisation or vasectomy before the woman reaches the end of her fecundity. This is a reflection of the need for certainty. It is equally a reflection of the distaste for the abortion of unplanned pregnancies after the couple consider that their family is complete. The late child arriving as an 'accident' and often, in an affluent household, having a benign and happy upbringing, is largely a phenomenon of history. Women feel a need once again for experience in a job outside the home and to use their skills and training either out of a compelling interest or to keep up the family earnings. There is also some anxiety among the well-informed about the increasing risk of a Down's syndrome baby born to a mother over 38 years of age.

Another consequence of this attitude of precise planning is the growth in the need for sub-fertility clinics, as many women are attempting to become pregnant for the first time at a later age. In the days of fatalistic resignation, childlessness was seen as a misfortune to be borne by some, just as hyper-fertility was to be borne by others. There were also more babies available

for adoption, usually arising from the unintended and unwanted pregnancies of younger people. Adoption mitigated the pain of infertility.

Vasectomy is a very simple operation, usually easily and quickly performed, possibly one of the most cost-effective procedures in health care today. After post-operative seminal clearance, failure due to spontaneous re-canalisation of one or both *vas deferens* is rare, probably at most one in 2000 cases, more usually one in 4000–5000. Female sterilisation is carried out by a variety of methods. Subsequent failures vary according to the method used, and to some extent with the experience of the surgeon, from about one in 100 to one in 500.<sup>24,25</sup> These figures apply as proportions of all operations rather than annual rates, so it can be seen at once that fertility control by sterilisation is much more effective than contraception. Female sterilisation is often carried out under general anaesthesia, incurring that particular hazard. And failure of the operation itself is hazardous to the woman, as a high proportion of subsequent accidental pregnancies are ectopic gestations, placing the woman in great danger from internal haemorrhage. Apart from these risks, the operation itself involves entering the pelvic peritoneal cavity and this may lead to more serious complications than, say, a vasectomy operation. Female sterilisation is encouraged in the NHS by the provision of special item-of-service fees for the surgeon and anaesthetist. Although substantial fees are similarly available for vasectomy within the NHS, by some incredibly foolish quirk of the policies arising from under-resourced health care, district health authorities only provide a very patchy service over the country as a whole, and many vasectomies, about 50 per cent, are carried out in the private sector.

Sterilisation, however, does not suit everyone. Experience in a counselling clinic shows that there is every variety of approach: from those enthusiasts who put in a request the day after the second child is born; to those who make their approach in their forties after a painful history of contraceptive problems, failures and unhappy abortions. In this clinical situation many truths about contraception are brought home to the family planning doctor. He will meet couples who have experienced failures or discomforts with all the methods

they have tried and others whose cases have clearly been mismanaged by their advisers. Therefore there are some, perhaps as many as a third of the couples applying, who are driven to sterilisation by fertility problems when they quite possibly would not otherwise have chosen this final solution. Equally, there is a substantial group of women who wish to maintain their potential fertility until well into their forties as they otherwise feel a sense of deprivation. They may never reach the intention of promoting a conception but they hate shutting the door on it. Men have a much longer span of lost potential fertility to regret and one of the important clarifications to be made in vasectomy counselling is that the man feels certain that under no circumstances is future fatherhood an option he wishes to maintain. Certainty comes through clearly: they have had enough of young babies in the home, although enjoying their growing children, and they find it easy to transform their sexuality into an infertile enhancer of relationships with no potential for parenthood. The impression remains that this transformation is more difficult for women, some of whom may retain at the back of their minds a strong link between sexuality and potential maternity. For this group careful consideration of contraceptive strategy will entail the use of a method as effective as it can be but without losing reversibility, however much this factor needs to be symbolic rather than real. With increasing age, intrinsic fecundity declines so that at the age of 40 a method with the effectiveness of, for instance, the progestogen-only pill will meet their needs adequately. At a younger age it may be necessary to consider a depot progestogen injection which gives a degree of protection of the same order as the COC pill. This group of women is not likely either to tolerate induced abortion with emotional ease.

Some women in their mid-30s and 40s have problems of uterine bleeding. This is sometimes accompanied by the nodules in the uterine wall we call 'fibroids', or sometimes without any demonstrable organic change. A generation ago hysterectomy in this age group was commonplace and this procedure was seen to solve several problems: removing the source of bleeding, removing a potential source of cancerous change and, not least, removing fertility. This operation is less lightly undertaken now. Many women used to feel a sense of

mutilation after hysterectomy and adverse emotional consequences were common, some believing for the rest of their lives that they had in fact had a malignancy removed that no one would tell them about. Today there are hormonal treatments to control bleeding problems and although hysterectomy is not at all rare it is carried out with more explanation, greater circumspection and with a care and concern for post-operative sexuality that was previously unheard of. It clearly remains a factor in the pattern of fertility control, but, for some women, the loss of potential fertility will be a source of grief. Much depends on the trauma or otherwise of their reproductive experiences and the emotional and physical quality of their sexual relationship. Unwanted pregnancies, problems with contraceptive pills or intrauterine devices, discomfort over barrier methods – all these can induce a desperate urge for a radical solution.

Sterilisation is therefore acceptable for many couples, especially vasectomy which is such a simple procedure. There will always be a proportion for whom it is not suitable and who wish to maintain fertility potential as long as nature allows it. There will be another group who have been forced into sterilisation, by one means or another, owing to traumatic reproductive histories or gynaecological morbidity, and who will need support for the loss of an important element in their lives. Vasectomy, for all its advantages, does not provide sexual freedom for the woman. This is a disadvantage difficult to discuss adequately at the time of a couple making a request for vasectomy, but it is a very basic change in the balance of a relationship if previously the woman has been using a highly effective hormonal method.

#### A view of 'natural family planning'

The range of contraceptive methods depending on the prediction of the day of ovulation in the menstrual cycle<sup>26</sup> is now embraced by the term 'natural family planning'. No contraception can truly be 'natural', as the natural side is unfettered fecundity. An important feature of these methods is that they are consistent with Catholic doctrinal teaching. In some respects, however, the Vatican appears to condemn any action

which enables sexual intercourse but reduces the risk of pregnancy. The philosophy behind this is that sex is for reproduction within a marriage. But there must be few among the Catholic laity who really accept this as a tenet of their faith. And it is also but a few, in this country anyway, who rely only on natural family planning.<sup>27</sup>

The appeal of those who prefer 'natural' ways of living comes from avoiding the need for any drug or appliance to disturb the physiology artificially or to intervene in the act of coitus. Some couples may use a natural method to predict ovulation and hence the three days either side, the potentially fertile time of the menstrual cycle, and then use, for example, a barrier method during the fertile days. This is reasonable provided the woman has regularly identical cycles over a prolonged time in her life – and many do. Abstinence during the fertile days is not always successfully maintained and this is one source of error – 'user-failure'. Another is simply mistaking the arithmetic or the signs – mucus change or temperature change. But a quite important third problem is the variability of ovulation itself. Even for women with regular cycles, ovulation can occasionally be delayed by stress factors such as emotional distress, illness, athletic training or competitive performance, or losing weight. Individual sensitivity is quite variable, but there have recently appeared on the market test kits for detecting ovulation time more accurately. These are at present very costly (for example, £25 for two cycles in 1986–7) but may help to reassure users of natural family planning who can afford to purchase them. There has therefore been an atmosphere of failure surrounding the natural or rhythm methods and experienced family planning clinicians do not, on the whole, encourage their users to try them.

The group of doctors, nurses and counsellors involved in the natural family planning movement take time and trouble with their work. They usually see couples together initially for up to an hour's discussion. The observations by the users needed for success in preventing pregnancy are carefully described and discussed in the context of sexuality and daily living. Those couples who attend for such advice may well benefit from the opportunity for such a wide-ranging counselling interview.

Whatever the merits or otherwise of this approach to

contraception, there is undoubtedly value in men and women being aware of how their reproductive systems operate; often women will become able to perceive bodily symptoms at the time of ovulation. This understanding and awareness can only be helpful, not only in contraception but in planning to conceive and in understanding some of the feelings and states as they vary during the menstrual cycle. There is an argument certainly for these matters to be included in health education in schools for girls, and indeed for boys too, thus demystifying the female processes and encouraging a trend to autonomy.

### Questions of consent

There has been considerable concern recently in the family planning press over the withdrawal from availability of a number of intrauterine devices which have been well-tried over many years and much appreciated by large numbers of users. The Saf-T-coil disappeared in 1983 after 15 years, the Lippes Loop in 1986 after over 20 years, and the Gravigard (Copper 7) in 1986 after 14 years. In the last case the manufacturers publicly pointed out the reason: that they were being subjected to litigation on a large scale and although successful in resisting such cases the cost of defence could no longer be contained and their insurers were refusing indemnity cover.

This is a sorry development and seems connected with the contingency fee system allowed to lawyers in the United States: that is, the case lost, no fee; damages won, a percentage to the lawyer. Doctors have expressed alarm over the depletion of contraceptive alternatives. At present women have been put off IUDs by the accompanying media reports, but such loss will undoubtedly be regretted in the long term.

The IUD has an important difference from barrier methods or oral contraceptives; it only requires the act of insertion by a doctor or other trained person on one occasion. Thereafter it is an active contraceptive agent irrespective of anyone's intention or desires until it is removed, again by a trained professional. On the one hand there is the convenience and advantage to the user of being able to forget all about it, at least until the next clinic visit is booked. From the doctor's point of view, the

woman has been 'fixed up' for a given duration and cannot change her mind, forget to use it or lose it, until she formally asks for the device to be removed. This gives the doctor, or other professional, a great deal of control. Some users may be quite happy with this balance of power: they may see themselves as unreliable over matters affecting fertility control for a variety of reasons: forgetful of routines, spontaneity of sexual responsiveness, or even divided motives which can sabotage their best efforts to maintain efficient contraceptive cover. There is perhaps an element of diminished self-esteem in handing control over to the doctor. Others, however, may not see things this way: they may desire autonomy, control of their bodies in their own hands.

The doctor's ethical position seems quite clear. Informed consent to the insertion of an IUD must be obtained beforehand. On a straightforward request for removal, the device should be instantly removed. There are various circumstances in which this position can be modified or, possibly, abused.

The most obvious example is in the case of a woman with mental illness or mental handicap. If an IUD has been inserted in such a woman, it may be tempting to all concerned with her care to leave it alone, whatever she says. It may be arguable if treatment is being given by an order under the Mental Health Act, that IUD contraception can be maintained equally under that order in the patient's best interests and to protect her against the dangers of pregnancy. Psychiatrists in charge of such patients are sometimes evasive when tackled by the family planner. Their position, it is suspected, is not clear in relation to non-psychiatric treatment. The doctor's intention, of course, is not merely to protect the individual, but in a large degree to 'protect' the unconceived potential child from a hopeless future. Worthy as these feelings may be, acting on them does not conform to any ethical stance and certainly does nothing to promote autonomy in the individual concerned.

Another example can occur when there is a procedure under general anaesthesia, for the most part a termination of pregnancy. Many doctors resent being obliged to do abortions and will sometimes use their position of control to 'fix' a woman up; that is, do something to protect her from fertility in a situation where freely obtained information consent has been doubtful.

All shades of this process sometimes occur in NHS abortion clinics: at one end of the range is the doctor who, tacitly or otherwise, only agrees to do the abortion if the patient agrees to have an IUD fitted. At the other extreme is the doctor who just inserts a device under the anaesthetic whatever the position regarding consent and may even 'forget' to explain this to the woman afterwards. If the thread of the device is cut short to the cervical canal at the same time, the loss of autonomy by the woman is complete. Patients have arrived years later at infertility clinics and it is not until there is a sonar scan, an x-ray of the pelvic area or a curettage of the uterus, that the IUD is discovered, perhaps after years of attempting to conceive. Such cases are rare but most infertility clinicians will have come across them.

The results of a study at King's College Hospital in 1975 demonstrated, without any particular evident explanation, that women using IUDs in the hospital family planning clinic were more likely to be manual working-class (or undesignated), high parity (especially including a history of multiple terminations), or black (mainly from families of Jamaican origin).<sup>28</sup> Those who know the area served – Brixton, Peckham and Dulwich – will realise that these characteristics are closely interrelated, but the findings lead to a stereotype of an IUD user in this clinic, which is confirmed from the findings of others. It is quite important to realise that these clinics are not manned, the author will testify, by an unusually authoritarian group of doctors. It is in the nature of the doctor-client relationship within the structure of a clinic that this bias in usage will appear. Doctors try to do good and try to help people. Often this may involve some degree of failure in promoting autonomy. Perhaps in the mid-1980s things might have been different, as the ethos of younger doctors became more client-centred, particularly among women doctors.

This difference in the social characteristics of the IUD user is worrying when put beside the propensity of doctors to 'fix' people up and then move on. Anxiety centres on the quality of consent where less assertive, less articulate, or less well-educated consumers are concerned, and whether they have first been stereotyped artificially as poor users of more autonomous methods and then been heavily persuaded to use a

doctor-controlled method. This seems to occur among young abortion patients as evidenced by Carolynne Skinner's study of pregnant teenagers in Camberwell.<sup>29</sup> Many of the IUDs inserted under general anaesthesia at the time of an abortion are removed a relatively short time later in family planning clinics or by general practitioners, when women who do not really want them and who do not believe they really consented to insertion, develop symptoms and request removal. There is no long-term benefit to the woman or the doctor in poorly consented heavy persuasion.

Another family planning field where a similar framework of care exists, lies in the use of depot injections of progestogens. One can end up with a happy and contented group of users; those who have been adequately informed and have freely consented. On the other hand, a family planning clinic may have a dissatisfied, resentful group of users, who feel they have not been told enough about side-effects, or that the information they were given was wrong.<sup>30</sup> Sadly, their protests will tend to be fed by material generally having no scientific foundation promulgated by radical groups. Here again in former years the stereotyping of the 'poor user' prevailed and many women suffered from the feeling that they had been harmed by an injection they did not understand. Furthermore, once given, the side-effects of the injection are likely to persist for many weeks as it is a depot injection: it cannot, as with an IUD, be removed on request.

The whole issue of giving contraceptive advice to very young women, in particular those under 16, has been aired recently as a result of the case brought by Mrs Victoria Gillick against her local health authority and the Department of Health and Social Security. She requested a court ruling that her teenage daughter would never be given contraceptive advice without Mrs Gillick's consent as her mother. After a series of dramatic swings, the case went to the Law Lords who gave their judgment in 1986, namely that under certain carefully defined circumstances, advice and treatment could be given without parental consent.

Previously doctors had shown great anxiety over the treatment of a woman under 16, that is below the age of consent to sexual intercourse, if she did not wish to tell her

parents about her sexual relationship. The man commits the offence, not the girl, and the severity varies with his age. In practice, little action is taken against a fellow-teenager. Doctors, however, were concerned that giving contraceptive advice without parental consent would be considered to be acting as an accessory to unlawful sexual intercourse. There was also the question of consent to a medical examination or treatment, especially a pelvic examination, should this be thought necessary or if, for example, a vaginal barrier was the method to be used. The position had been covered by a DHSS *Memorandum of Guidance*, originating in 1974, modified in 1981, and again in 1986 following the Gillick judgment (Appendix to HC(86)1/HC(FP)(86)1/LAC(86)3). Mrs Gillick challenged the validity of the Memorandum and was upheld by the Court of Appeal. The Law Lords rejected this challenge and the legal position of the doctor was then similar to that in 1981.

As before, the overall view was that the doctor should be given discretion to act in what he regards as the patient's best interests in protecting her physical and mental health. Five criteria were laid down about which the doctor had to be satisfied:

- 1 that the girl will understand the advice;
- 2 that he cannot persuade her to inform her parents or to allow him to inform the parents that she is seeking contraceptive advice;
- 3 that she is very likely to begin or to continue having sexual intercourse with or without contraceptive treatment;
- 4 that unless she receives contraceptive advice or treatment her physical or mental health or both are likely to suffer;
- 5 that her best interests require him to give her contraceptive advice, treatment or both without parental consent.<sup>31</sup>

All this places a subjective onus on the doctor, but on the whole it should be reassuring. In the first place, many young teenagers involve their parents when a relationship becomes serious enough to require contraception from a doctor. In cases where this is not so, the family circumstances of the

young woman are quite often so adverse that the doctor is unlikely to feel in doubt about the merits of his actions. It is some consolation that the majority of judges have always regarded an unwanted pregnancy as a considerable stress factor for a woman and have supported the idea that it should, if possible, be prevented.

The question of consent to sterilisation in a mentally handicapped young woman has recently been considered in the Court of Appeal. Lord Dillon, with concurring colleagues, gave judgment in favour of sterilising a 17-year-old who was said to have the 'mental age of a five-year-old' and not to be able to connect sex with pregnancy. She was a ward of court at the time and it was not considered that consent to sterilisation should be given in any other way – for example through parents or guardians *in loco parentis*. As the issue is one of great importance, the Official Solicitor appealed to the House of Lords on behalf of the young woman. The Law Lords upheld the judgment of the Court of Appeal.<sup>32</sup> It follows that consent to sterilisation in such a case could not be obtained once the woman reached the age of 18 and could thus no longer be a ward of court.

Consent by young people generally may be given by them at whatever age they understand the nature, purpose and risks of what is to be done. The principle applies, stated by Lord Denning, that the rights of the parents decline as the child becomes older and more able to understand these issues for herself. It is hard on young women that there is a vocal minority pressure group constantly attacking their autonomy and their access to medical care in this area. Young women are the sufferers throughout these struggles and those in most need of help from their general practitioner or family planning clinic are frequently the least well-educated or articulate in our society. It is the experience of workers in youth advisory clinics that they come from severely disrupted homes where there may be regular violence or drunkenness.<sup>33</sup> Some are themselves the unwilling victims of incestuous fathers or stepfathers. Their tendency to form sexual relationships with a boyfriend relatively early in life reflects their need for some kind of emotional comfort and security outside the home. For this group to find doctors uncertain or unwilling to help them,

when they do summon up the courage to go to a clinic, seems particularly hard. Brook Advisory Centres reported (Annual Report 1986) that their younger clients just disappeared during the Gillick hearings. It was at least a year after the Lords' judgment before they started to return to what was for many the only available source of advice and counselling from an older group of people.

### Doctor-patient relationships

We have seen how there are particular needs in family planning work for the sharing of information and the involvement of the user in making decisions about the type of method to be used and the overall contraceptive strategy. Earlier, it was emphasised that the risks of the more interventionist methods with their high degree of efficiency require special consideration when balanced against their benefits. The user population consists of mostly healthy women in the reproductive and family-rearing age group. Any harm will have a devastating effect on family life in this group in addition to the individual loss or disablement and the grief it brings.

The combination of care and sharing in the intimate area of sexuality and reproduction entails that the professionals give special value to cultivating a relationship in which they may be effective in all these ways. There must be a great deal of mutual trust and this usually needs to be preceded by mutual understanding. Doctors in this situation must show something of themselves if the patient is to be correspondingly revealing. They must be able to develop an honest rapport and this will imply an equal type of relationship rather than one of authority. After all, it is intended that the patient, or 'user', will be making most of the decisions for herself, or the couple for themselves. The doctor who lays down a plan, however benign, may well find that the user fails to persist in following that plan which she may feel is imposed outside her own volition. The doctor cannot be there all the time for constant reinforcement. The plan will then fail and many an abortion request has arisen in just this manner.

Doctors are usually very different kinds of people from their patients, often from a middle-class background and trapped as

they have been for the most part and for many years in the constraints of medical education and 'being a doctor'. Nurses may be less adversely affected by their training, but a cover of professionalism is inevitable and may indeed be essential for their emotional survival. Nevertheless there are mechanisms for bridging these gaps, which are not all dependent upon relative affluence or power of articulation. Doctors and nurses need to cultivate a sense of how their patients live and what are the important issues to them which bear upon decisions affecting their fertility and sexuality.

Such skill and knowledge will be of particular importance in providing care for the special groups: adolescents, mentally and physically handicapped, and people from a different cultural background, possibly with added problems of language. Young people's advisory clinics have grown up and proliferated as a result of the farsighted initiative of Helen Brook and her colleagues, who developed the requirements, the structure and the professional skills for providing a contraceptive service for young people. The actual number of Brook Advisory Centres in the whole country is relatively small, but the influence of the organisation is much greater and many health authorities have provided clinic sessions in the Brook style as part of the statutory services. The role of the Brook Centres has also been extended through their provision of educational materials and publications for groups in society with special problems.<sup>34</sup> An example of this is a series of information leaflets for young people with reading difficulties.

Inevitably women are more concerned with the clinical side of family planning than are men. Condoms and vasectomy are the 'male methods' – although many would assert that condoms are a joint method if they are to be used in the most regular and effective way. So with present technology, women are necessarily in the front line for the intervention in their physiological processes required to prevent fertility. With all the elements needed for successful doctor-patient contact, it is obvious that female doctors are more likely to be in demand than male doctors. For several reasons, particularly career opportunities, women doctors have dominated the family planning clinic field from the beginning in the early 1920s. It was not until 1975, when the male-dominated army of general

practitioners entered the NHS system for providing contraception, that there was a balance of the sexes numerically. To some extent this has added to a sense of polarity between the clinic doctors and the general practitioners which lingers on even 12 years later.

Male doctors vary in their approach to women and much will depend on their sense of comfort or otherwise with their own intrinsic sexuality. Wendy Savage, in a recent radio broadcast (1987, Radio 4), described two kinds of male gynaecologist: those who loved women and those who hated them. This may seem an extreme view, but clearly the underlying feelings within doctor and patient will affect the quality of the consultation and ultimately the standard of care. In family planning, unperceived emotional blocks may seriously vitiate communication. There is also the factor that when there is a choice between two unknown professionals, women will usually prefer to consult another woman. They will expect more understanding, an easier empathy; and this is usually completely justified. They may also feel anxious about intimate physical examination by an unknown male. The choice of seeing a woman doctor or nurse should usually be available to family planning clients. It is up to the managers of the services to ensure that all the doctors and nurses are sensitive and skilled enough for effective family planning work.

In general practice, the element of choice is bound to be more restricted. There are many more men in that branch of medicine and the power structure of partnerships and groups tends to be in the hands of the male principals. They are usually older and more likely to have been fully involved all their working lives with the building up and organisation of their practices. General practitioners are consulted more often by women patients, either for themselves, or as mothers, or as carers for infirm relatives. On the behavioural side, they may well have developed a comfortable and caring relationship with women. On the practical clinical side, they may be less certain. In continuing education there is always great interest in family planning topics although the technical content is less demanding than, say, cardiology or neurology.

Again, when it comes to consulting their general practitioners

about intimate but vital matters relating to sex and reproduction, women patients may well prefer to go to women practitioners where they can feel more on equal terms and expect mutual female understanding. However, for the cure and care of their pathologies – a situation naturally entailing a more dependent role for the patient and a more prescriptive one for the doctor – they may well consult a male GP. With more women entering medicine, and more now also entering vocational training for general practice, opportunities are arising for most groups or partnerships to include women. Their recruitment depends on the good sense of the established males which, it is earnestly hoped, will not be lacking.

### Population and family planning

Malthus propounded that unrestricted births would increase the population in a geometrical progression.<sup>35</sup> He stated that resources could only increase arithmetically and that therefore even the most affluent of societies would eventually all starve. The idea of 'birth control' came into being. He considered, however, that artificial contraception was utterly immoral. Society was to be saved by the sexual continence of those who could not afford to keep a large family. This policy would be applauded by the Roman Catholic hierarchy who promote the belief that sexual intercourse should occur only for the production of children within the setting of a family.<sup>36</sup> Both these attitudes towards sexual behaviour are entirely unrealistic for the greater part of the adult population. The urge towards sexual activity is evidently too strong for a philosophy of this kind to be practically successful.

In modern times, John Stuart Mill was among the first public figures to promote artificial contraception, no doubt with some Malthusian ideas in the background but chiefly to promote the liberty of individuals from the burden of excessive child-bearing. He was a friend of Francis Place, the tailor from the Strand, who tried to popularise contraceptive vaginal sponges.<sup>37</sup> This dual thread, of population control and of individual freedom, has run through the birth control movement ever since. There are those who support the wide availability of contraceptives for the relief of individual

suffering, for example the women pioneers who put together the Family Planning Association in the period between the two World Wars. A major boost in the movement came immediately after the Second World War from scientists who, like Malthus, feared that an indefinitely increasing population would cause starvation for all. International promoters of family planning are driven by the need to replace war, famine and disease by more humane ways to control population. Famine or conflict as a means of controlling populations involve enormous suffering at the time of the disaster and afterwards, and there is no question, therefore, as to which is the civilised approach.

In a free society, the extent to which individual couples will limit their families by voluntary birth control depends greatly on their economic status. Deprived families will tend to be larger, not only because it may be difficult for the parents to obtain contraceptives but because of the belief that, when there is no material wealth, another baby represents an asset.<sup>38</sup> If only the family can survive with enough children to reach the next generation, they will provide some future security for the ageing parents. In the meantime the children's work may increase the assets of the family towards a more prosperous level. Survival is the doubtful criterion. Malnutrition stalks through such social groups repeatedly as crops fail or war-lords take their toll. The Malthusian ideal has only been successful in modern times with harsh socio-political regimes, as with New China for example where serious sanctions were imposed if more than merely replacement births occurred, and sterilisation was compulsory. The population of China was one of the greatest contributors to the hyperbolic curve of world population increase: it is no longer in this position. Other countries, such as Singapore, have used powerful economic sanctions, with serious loss of economic rights for the third child or more. Not all developing countries adopt such policies. Some believe in an expanding population to soldier their armies and provide the means for nationalistic expansion. In some African countries, disease and infertility are so prevalent that these policies do not necessarily lead to population increase. Once aid, investment or development leads to improved nutrition and a reduction in infant mortality,

the promotion of voluntary birth control becomes an important factor in the survival of the trend towards a better life.

What of the affluent West? Since the 1960s populations have stabilised in Europe, including Eastern Europe, in North America, the white Commonwealth, and the USSR. In the two post-war decades, it was the custom for middle-class couples in the UK to settle for two children on average for earnest demographic reasons. There was a feeling that it was immoral to have more. The move towards the two-child family did not really extend throughout society until the wide scale provision of family planning, including sterilisation, became issues of public policy at the end of the 1960s, together with the implementation of the 1967 Abortion Act. The integration of contraceptive services fully into the NHS in 1975 completed this process.

Small families are now the norm, but this is not so much caused by public-spirited attitudes towards voluntarily reducing world population growth, as by growing expectations of high living standards. Many young couples in central London – for example, a skilled craftsman married to a secretary – hope to put down a mortgage deposit and move into their own home outside central London within their first two years together. Children will then be precisely planned to arrive at times when the mother's earnings can be spared for a while and in an overall plan to acquire the requisite consumer durables. With this sharp contrast to earlier days, unplanned pregnancies and subfertility come as something of a shock. Since 1979, however, unemployment has become a major feature of inner city life, changing in particular the patterns of living among deprived young people. It is more difficult and less likely that stable families can be initiated. The mother of possibly unplanned conceptions may set up in a single parent home on her own, with fair support from a socialist local authority, and most are unlikely to venture beyond a second child in this situation.

The demands on the family planning services are therefore for results far more precise than those of 25 years ago. Expectations have risen with the newer contraceptive technology, biologically invasive though it may be. Abortions remain high for women in their late teens and early twenties,<sup>39</sup>

although the standard of care in NHS units has declined with the fall in resources available to clinical departments. Sterilisation remains immensely popular in the later age group, whose members have had their precisely planned number of children.

As a general practitioner in 1960 I recall visiting a tenement flat where the only bedroom, the children's, had no floor space between beds and to attend to the sick child I had to clamber from the door over several beds. There were seven children, three caused by diaphragm failures, before the young indigent couple could be persuaded to add serious contraceptive efforts to their happy sexual relationship. After ten years, the council found them a double-sized flat, but by this time the father was one of the long-term unemployed. Such large families arising from the same two parents are now only seen rarely in South London among the indigenous white population.

Meanwhile in the wider world, population growth has continued its hyperbolic rise.<sup>40</sup> A major decelerating effect must have come from the strict control of births in New China as its population numbers a significant proportion of the world's total. India and South America remain, however, relatively uncontrolled. It is now fairly generally agreed that small families arise when economic development allays the hopelessness of poverty. If parents are given some expectation of a future life with reasonable shelter and nutrition, education for the young and social care for the old in a well ordered society, intended family size will fall. It is then up to family planning services to provide methods of fertility control which avoid those threats to women's life and health that come from unofficial abortions and folk lore. In the early stages of the transition, legalisation of abortion is a vital step in providing safe operations and bringing people into contact with contraceptive and sterilisation services. Primary family health care units can cooperate in this, and it is an important principle that every paediatrician in the developing world should be working side-by-side with a family planning unit. Reduction in child mortality can strangle a poor community unless resources are increased and births decreased. The Vatican has not been helpful on these issues, particularly in Central and South America.

Twenty years ago population increase was regarded by some Western authorities in isolation, and family planning teams were set up by the 'do-good' nations to be flown into areas of high birth rate, to 'fix-up' all the women with modern contraception and fly out again. This type of scheme unfortunately set back the clock of family planning acceptance on a wide scale. Such a community feels threatened by the invasion of affluent aliens determined to cut down their breeding. The reaction is one of suspicion, and methods may be accepted only later to be dropped when the team has gone away. Accusations of 'neo-imperialism' were made. On the other hand, a more integrated approach with early local political acceptance and the Westerners providing technical assistance and training to a home-based programme, can be of immense help to a developing nation. Mauritius and Thailand are examples where such family planning programmes within a governmental structure have averted critically high population growth rates which could have led to the destruction of communities by famine or conflict. Successful family planning for the whole population is thus part of a complex developmental network. The contribution of the Western nations should be to promote socio-economic advance generally, with family planning as a part of the pattern to be taken up by the people when they are ready for it.

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I have already indicated that a major cause of the increase in litigation is people's greater awareness of their rights. After all, any medical practitioner looking at the problem objectively would find it hard to argue that if a victim is entitled to compensation he or she should not take action to receive that compensation simply because the person responsible for the accident is a doctor. Doctors would not say this about a traffic or industrial accident for example, and there is no justification for saying it about a medical accident. All AVMA has done and continues to do in relation to litigation is to try to make people aware of their right to compensation *if* there has been negligence, and to make it easier for them to obtain that compensation if they are entitled to it. Again I cannot really see that any honest doctor could quarrel with that.

Despite the points made so far, the reaction of the medical profession towards this increased attention to medical accidents has been mixed. There have been, as there always will be in any profession or society, those who have resented *any* such attention and have adopted the attitude that doctors perform such a valuable service to society that any attention that diverts them from that service amounts to harassment and should not be allowed. Even today, I hear or read of doctors saying, 'Look at all we did for her; we saved her life and just because the result is less than perfect she has the effrontery to complain'. The more responsible members of the profession have recognised the problem and have sought various ways in which to meet it. The British Medical Association has, for example, begun an investigation into a system of so-called 'no fault compensation' which is in operation in New Zealand and Sweden under which patients are compensated for medical accidents without an enquiry into how the accident was caused. They believe that removing the question of negligence from the enquiry into a medical accident will lead to untold benefits for the victims. I must point out, however, the difference in the BMA's attitude now – when doctors appear to be under threat from the increase in litigation – from its attitude at the time of the Pearson report.<sup>1</sup> The Royal College of Physicians has also reacted positively. In 1985, it held a one-day conference to consider medical accountability in relation to medical accidents and extended an invitation to AVMA to provide the

keynote speaker, and it has continued to give close attention to the problem. Other royal colleges, such as the Anaesthetists and the General Practitioners have expressed a sympathetic interest in AVMA's work. Other doctors have personally contacted AVMA and offered support. Generally, therefore, it could be said that the medical profession has shown a cautious acceptance of the increased public awareness, the need for change and the work of AVMA in this field.

Recently, however, there appears to have been what I can only describe as an ominous shift in the attitude of at least one branch of the profession – the obstetricians. They, of course, see themselves as being in the front line as far as claims for medical negligence are concerned. Although the number of perinatal deaths in the UK has dropped dramatically this century, there has been no corresponding drop in the number of babies seriously brain-damaged at birth.<sup>2</sup> Indeed, as a direct result of the advance in medical expertise, it may be that the number of brain-damaged children who survive has increased because of the reduction in perinatal deaths – the baby who would otherwise have died perhaps 30 years ago is now able to 'survive'.

Because of increased public awareness of medical accidents, many more people are attributing the damage caused to their babies to the circumstances of their birth, and are enquiring as to whether those circumstances have anything to do with the fault of the doctors involved. We must bear in mind the catastrophic results which can flow from this type of accident, and the cost in both economic and social terms to the parents of a brain-damaged child. Given that the only way in which parents can be compensated or receive realistic support for the care of their child is to establish that the doctor has been negligent (that is, has failed to handle the birth in a manner considered acceptable by his or her peers), it is not surprising that they wish, and are encouraged, to take the essential legal action. Indeed, it is not only the AVMA that encourages such action. A number of paediatricians, faced with children needing massive help, are themselves encouraging, or even suggesting, that parents take legal action which involves accusing the obstetrician of negligence. As a result, obstetricians are not only finding themselves more often the subject of

## Types of commissions

### *Ad hoc panels*

My first task, then, is to explain what I have in mind as the four types of commissions on medical ethics. The first is the ad hoc panel. This has been, as I understand it, the approach taken here in the United Kingdom, where commissions such as the Warnock committee on alternative methods of human reproduction have functioned successfully. In the United States, too, ad hoc panels have been used; indeed, the first major forays into this general field were of this sort. For example, the Department of Health, Education, and Welfare (DHEW) during the late 1960s and early 1970s established several ad hoc bodies to examine the implications of transplanted and artificial organs, such as the totally implantable artificial heart.<sup>1</sup> I think it is noteworthy that such bodies returned several times to this same topic and yet their recommendations did not seem to have much impact on the activities of the Department nor on the development of public policy generally. The absence of follow-through is a decided risk of ad hoc groups when the topic is not one that can be disposed of in a single legislative or administrative stroke.

In 1972, a journalist uncovered a research project that had been going on for 40 years among black men in rural Alabama. Several hundred men had been involved in this government-sponsored study of untreated syphilis. The study was begun in 1932 prior to the development of effective therapies for syphilis, but it continued up until the time that it was revealed to the public, which was plainly shocked to discover that scientific curiosity had apparently won out over medical care in the treatment of the victims of this disease in the study group. As a consequence, the DHEW established the Tuskegee Syphilis Ad Hoc Advisory Panel made up of distinguished physicians, ethicists, lawyers, and others. Within a few months they issued a report directed both at the particular problems caused by this study and at the larger issue of government regulation of scientific research conducted under government auspices.<sup>2</sup>

It is characteristic of this first type of committee that groups, usually of about a dozen people from medicine, law,

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economics, ethics, and often a few with prior government service, attempt to reach fairly concrete recommendations and conclusions on a specific subject. Further, such groups are usually staffed by the agency that set them up, which is usually interested in specific fact-finding and recommendations on an immediate problem. Sometimes larger recommendations about the general process may also emerge, as they did from the Tuskegee panel. That body was effective in clarifying most of the facts, though some crucial facts about the degree of intentional deception of the participants were not uncovered. One panel member has now publicly stated that he believes these facts may have been intentionally suppressed and kept from the panel.<sup>3</sup>

#### *Single-subject standing bodies*

The broader recommendations of the Tuskegee panel were quickly overshadowed, however, by the creation of another governmental commission in 1974—the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. I will use this group to illustrate the second category in my list—a standing body with authority to study and make recommendations on a narrow field within medical ethics.

The creation of the National Commission had the same provocation as the Tuskegee panel: namely, revelations about human experimentation run amok. In 1972 and 1973 the Congress of the United States took special interest in this subject. In particular, Senator Edward Kennedy, then the chairman of the Senate Health Subcommittee, held hearings on this topic, during which a number of troubling cases, in addition to the Tuskegee study, were disclosed, particularly research in prisons and mental hospitals and research on human fetuses. As a result, provisions were included in the National Research Act of 1974:<sup>4</sup> namely, that each institution conducting federally-supported research with human subjects was required to create an institutional review board (IRB); and an eleven-member commission drawn from medicine, research, law, ethics, and related fields was to be appointed by the Secretary of Health, Education, and Welfare. As a result,

## DEFENSIVE MEDICINE: MYTH OR REALITY?

Arnold Simanowitz

The issue of medical accidents has been receiving a great deal of public attention during the last few years. This does not mean that it has had no attention before that. It has always been a problem and from time to time a particularly lurid or sensational case receives the full public treatment – witness the case of Whitehouse and Jordan in 1980 or Sidaway in 1985.

Indeed, it was of sufficient interest to cause the Pearson committee, which investigated damages for personal injuries generally in 1973, to look at the particular problems of medical accidents. At that time, however, the British Medical Association was sufficiently confident – some might say complacent – about the size and manageability of the problem to say that it did not consider that any change in the method of dealing with compensation for such accidents was necessary. In recent years, however, the publicity given to medical accidents has increased dramatically, so much so that it is reasonable to say that hardly a week goes by without some reference to the issue in one or other section of the media. There are many reasons for this increase and it is not my purpose or intention to deal with all of them in this chapter. It is useful, however, to look at what I consider are some of the major causes.

First, it has to do with the general increase in public awareness and the desire of people to know more about, and to be able to take part in, decisions which affect their lives. This awareness has led, for example, to the creation of organisations like the National Council for Civil Liberties, numerous self-help groups, tenants' associations and law centres, and has even resulted in the opening up of such bastions of secrecy as local authority committee meetings. Second, the enormous strides

in technology have meant that when accidents happen they are more often catastrophic. For example, the anaesthetic accidents which led to bright, active, young people being turned into nothing more than vegetables. Accidents of this kind will always be newsworthy and are played up by the media for all they are worth. It is possible that the increase in the number of accidents is also a factor. But this is very difficult if not impossible to gauge because the figures are not available; and even if they were, it would not be clear without the necessary research whether accidents are increasing or that more have come to light as the public becomes more aware of its rights. Nevertheless, it would not be surprising if the number of accidents has increased as doctors, nurses and other health staff work under increasing pressure from the reduction in staff and services and as surgical operations become more technically difficult. Third, there is the activity of Action for the Victims of Medical Accidents (AVMA), a charity founded four-and-a-half years ago to help people who have suffered in this way. It is not AVMA's aim to increase litigation for litigation's sake, but to ensure that people are aware of their rights and are able to enforce them. It also tries to influence the health professionals so they change their attitudes towards the whole problem of medical accidents with a consequent improvement for victims. Clearly, both sides of AVMA's activity have led and will continue to lead to increased litigation and public attention to this long-neglected problem.

It is important to remember that the problem of medical accidents, however it is regarded, is not one that was created by AVMA. If you look simply at the problem of the accident itself this is something that has always existed. Contrary to the popular belief that was fostered by the medical profession, at least until fairly recently, doctors are human beings with the same fallibility as others. This means that they will make mistakes. Some of these mistakes will be unavoidable and, under our present system, will not be amenable to compensation; some of them will be avoidable or negligent and the victim will be entitled to compensation if he or she can prove that the accident was due to negligence. The existence or otherwise of AVMA cannot have affected in any way the extent to which accidents take place. And neither was medical accident litigation invented by AVMA.

claims for medical negligence but the size of the claims is greater than in most other fields – often running into more than £500,000

The obstetricians therefore have a vested interest in mounting a full-scale attack on the increasing amount of litigation and the large sums of compensation awarded by the courts. The way they are doing this is to try to persuade the public that litigation is actually making it difficult for them to practise medicine. They seek to frighten the public into believing that lawyers and increasing litigation are going to be the cause of patients not getting proper treatment because doctors will be making decisions, not on the basis of what is good medical practice, but on the basis of what will keep them safe from litigation.

In 1985, I attended a conference at the Royal College of Obstetricians and Gynaecologists where this point of view was put forward with terrifying force, speaker after speaker endorsing it in the most lurid terms and one of them going so far as to say that if the situation got much more out of hand he would give up medicine altogether.

It is of course not only the obstetricians who are trying to advance this theory, which underlies the idea of defensive medicine. The entire medical profession is slowly becoming obsessed with it. In essence, what the theory of defensive medicine says is that because of the increased litigation doctors are carrying out certain treatments, or refraining from carrying out certain treatments, not because they consider that that is the correct thing to do from a medical point of view, but because they are concerned about their legal position.

Now the first thing I want to challenge is whether this is in fact the case. I know that it is possible to find doctors who will actually say that they are behaving in this way. I wonder, though, whether any doctor, having given real thought to a case before him, can put his hand on his heart and say that he carefully weighed up that case and decided that, given the clinical indications for two alternative procedures, he chose one because it would not lead to litigation. I think they should be very careful before they do say that, even if they think it. I would have thought that if they admitted to acting in this way there would be a case to be put before the General Medical

Council of gross professional misconduct. Is it not misconduct to carry out procedures for other than medical reasons? The General Medical Council itself is not yet prepared to express a view on this. That is probably because at the present time it does not, as I do not, accept that doctors are practising defensive medicine. In recent correspondence with the General Medical Council, in which I put forward this proposition, the President expressed the view that, 'While in the present climate of society in which medicine is practised in the United Kingdom some doctors *may* have felt driven to adopt what may be construed as a defensive attitude, this Council and its education committee continue to urge the profession at large to improve their techniques and standards of communication with patients'. I am not quite sure what all that means save that it is clear that the President does not accept that defensive medicine is being practised.

I would suggest that even a doctor who would be prepared to brave the wrath of the GMC and admit that that was the motivation might well be confused himself. It is easy to say that you are doing something because you are watching your back. In truth, all but the most cynical and perhaps incompetent doctors will be moved to carry out a procedure because they believe it is a safer procedure. It will of course follow that the safer procedure medically is also the safer procedure legally. What is wrong with that? If we look at just two examples we can illustrate the point. I have been told that many more doctors are having x-rays taken for minor head injuries than in the past, and this is because if they fail to do so and there is a haemorrhage they could be sued. I am appalled if that is true. Should they not be more worried that their patient might die than that they will be sued? Surely the reason they are taking what might in most cases turn out to be unnecessary x-rays is out of concern for their patients? The other example relates to childbirth. It is argued more and more (with, I may say, very little back-up evidence), that the number of Caesarean sections is increasing in this country because of defensive medicine. The fact is of course that carrying out a Caesarean section is no guarantee of immunity from litigation. If a doctor having carefully considered the situation decides to proceed with a natural childbirth then, provided it is a decision which can be

supported by a responsible body of medical practitioners whatever catastrophe follows, the doctor will not be held to be negligent. If, on the other hand, that doctor decides to carry out a Caesarean and something happens to the mother (even, for example, an unavoidable anaesthetic accident), the doctor could be sued for negligence for carrying out an unnecessary Caesarean in the first place.

The position seems to me to be admirably summed up by, of all people, an American doctor – Dr Raymond Scarlette, Chairman of the American Medical Association's Committee on Professional Liability – who said in his report to the American Medical Association's House of Delegates in 1984 that 'Defensive medicine is also defensible medicine'.

I would like just to try to put this theory of defensive medicine into perspective by moving out of the medical world for a moment. The medical profession likes to see itself as unique and, in general, the public colludes with this view. But without in any way denigrating the doctor's role in society, it is necessary to recognise that many people bear, in their work, as great a responsibility to the public, if not greater. A train driver, approaching a corner at 100 mph with a load of perhaps a thousand or more passengers has to make a decision as to whether to slow down or not. A thousand lives depend on his decision. He makes his decision on the basis of the safety of the passengers, not on whether, if he does not slow down and he has an accident, he may be sued for damages for negligence.

The origin of the theory of defensive medicine, like so many barmy theories, is of course the United States. There the amount of compensation paid out to victims of medical accidents has risen so much that American doctors are being required to pay astronomical amounts to obtain their insurance cover – some of the top obstetricians have premiums of as much as \$80,000 a year. In the USA, the medical profession considers that the situation has reached such a crisis point that not only are doctors forced to practise defensive medicine, but an appreciable number are giving up medicine (or at least obstetrics) for this reason. If, therefore, an American obstetrician says that when he comes to deliver a baby he sees the spectre of litigation he might be justified. But for a British doctor to say it, as one did on a recent Panorama programme, is sheer fantasy.

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Even in America, however, the picture is by no means a clear one, and although it is accepted that to some extent defensive medicine does occur it is by no means accepted that this is a reasonable response to the problem of medical negligence litigation. Facts are almost as hard to come by in the USA as in Britain on the issue of medical negligence (or malpractice as it is felicitously called in the USA). A report on medical malpractice to Congress by the United States General Accounting Office in February 1986 was headed, 'No agreement on the problems or the solutions'. I do not propose to go into the details of the argument in America. Attitudes to malpractice and defensive medicine there depend on the standpoint of the person expressing the attitude. On the whole, consumers and lawyers see malpractice suits as the only way of maintaining standards in the medical profession. The comments of the American Association of Neurological Surgeons were, however, that, 'Defensive medicine in surgery is a reality. In terms of insurance and legal jargon this is "prudent" practice and only a fool would not engage in such practice. The cost of this is not measurable but may run into \$30 billion a year'. According to the American Medical Association, professional liability insurance premiums for physicians in 1984 represented about 8 per cent of their 'before tax income'. I would just point out that on that basis the premiums of \$80,000 to which I referred earlier would presuppose a before tax income of \$1,000,000!

For the purposes of this discussion, I accept that defensive medicine is a problem in the United States. What I challenge is whether it should be a problem here to the extent that it is a problem there.

The American situation has come about for at least four reasons, none of which applies in this country. Firstly, it is recognised that the Americans are a particularly litigious people who reach for their lawyer as soon as they feel they may have been wronged in any way. Secondly, the fact that in America medical treatment is based on the profit motive leads to a totally different relationship between patient and doctor whereby the patient demands value for money and will litigate to ensure that he or she gets it. Thirdly, there is the system of remuneration for lawyers. The American lawyer is paid on a

contingency basis. He or she takes a percentage of the damages. In other words: no win, no pay. The size of the percentage varies but it averages about 30 per cent. I do not intend to become involved in the debate which is now raging in legal circles here – as to whether this system is a good one or not. It does have certain advantages. What is not in doubt is that the American lawyer has a vested interest in the size of the award. What is also not in doubt is that because of the amount of work involved in preparing a malpractice suit properly most American lawyers will not touch a case which is likely to be worth less than \$100,000. I cannot say that this system will never come to England. Indeed, the Law Society may already be contemplating a limited version of this system which will apply to tribunal cases. Be that as it may, it is not a system that applies today and it therefore does not have any influence on the size of damages awards in this country.

The single most important reason why the sort of 'malpractice crisis' experienced in America (and I put that in quotation marks because, as I have indicated, the nature of the crisis is by no means clear) cannot happen in this country is the difference which exists in the legal procedure. I believe that this difference is not widely appreciated outside the ranks of the legal profession. In America, it is the jury which decides not only whether the doctor is guilty of negligence but also, if he or she *is*, how much the victim should get. A persuasive advocate with a pathetic story can easily wring as much as \$8,000,000 for a brain-damaged child out of a sympathetic jury made up of mothers and fathers. In June 1986 I attended by invitation the Annual Conference of the Association of Trial Lawyers of America. There I saw an example of a video tape used for this purpose. Entitled 'A day in the life of ...', it showed the day of a brain-damaged child with its parents in vivid detail. What jury could fail to be moved to make a finding of negligence against the doctor, and to give the parents whatever sum in damages their lawyer was seeking? The American Medical Association has gone on record as saying that the crisis is due not to the increase in the number of claims, which is moderate, but to the size of the awards: 'While the increase in numbers of suits and claims is unsettling, the real problem lies in the tremendous growth in severity – or cost – of claims.'<sup>3</sup>

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In this country, the highest ever award was some £1,000,000. With the judges in control of the awards they will rise only in accordance with inflation and possibly to some extent with the greater appreciation on the part of judges of the needs of victims.

I would like to end by speculating a little on how this myth of defensive medicine has been allowed, if not encouraged, to grow in this country. I have already suggested that to some extent it is the profession trying to claw back some of the sympathy which it feels it has lost in the last few years to the plight of the victim. And here I must make it clear that I am not suggesting that all over Britain there are little groups of doctors gathered in dark corners plotting how to take back the initiative and seizing on the 'defensive medicine' ploy. It is simply a question of those in the profession who do think about these issues, reacting emotionally to the attack upon them and articulating half-baked ideas which have an appeal.

I know that many of the 'opinion formers' and leaders in the profession in this country actually do not go along with this myth. However, they take no steps whatsoever to counter it. Why were there no officers of the MDU at the conference of the Royal College of Obstetricians and Gynaecologists to which I referred, refuting the extreme statements being made by some very eminent speakers on this topic? Why has the GMC not come out in condemnation of the consultants who go on TV and wind up the public on this topic?

I believe that defensive medicine is a myth and I believe that responsible doctors in this country believe it is a myth. But why are they not stating this message loud and clear?

### Notes and references

- 1 I have discussed this and other matters relating to 'no fault compensation' in medical accidents: the problem and the challenge in Peter Byrne (ed). *Medicine in contemporary society: King's College studies 1986-7*. London, King Edward's Hospital Fund for London, 1987.
- 2 I have been taken to task on occasion for my use of the term brain-damaged and for referring to the relationship between the problems at delivery and such damage. I am not medically qualified but I use

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terms and concepts which are recognised by lawyers and doctors alike without embarking on my own medical research. Until it is established that brain damage, as the courts understand it, and anoxia and other birth difficulties are not related, I must continue to use these concepts.

- 3 Professional liability in the eighties. Report of the AMA's special task force on professional liability. October 1984, page 11.

## A NATIONAL COMMISSION ON MEDICAL ETHICS?

Alexander Capron

I have been asked to describe the work of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which operated in the United States from January 1980 to March 1983, and to relate the Commission's work to the possible existence of such a body in the United Kingdom. I plan therefore to do three things. First, I will outline the four types of commissions on medical ethics with which we have had experience: an ad hoc body, a standing committee with a mandate for only a narrow field, a standing body to study and make recommendations on a broad field, and a standing body to review and take action on specific problems. Second, to elaborate on the third option, I will describe the structure, functions, and accomplishments of the President's Commission. Finally, I will try – somewhat dispassionately, I hope – to evaluate the desirability of having a standing commission on medical ethics or, as we might say in the United States, a commission on bioethics. In the process I will touch on such concerns as whether it is a forlorn task to seek to take on the whole field of bioethics; whether there are unifying themes that make such a broad scope not merely possible but actually desirable; whether such a body should have rule-making or merely recommendatory powers; and what audiences such a body should usually and effectively address (that is, whether it should be concerned solely with the agency that appoints it or with other public and private bodies).

the National Commission for the Protection of Human Subjects was appointed by Secretary Caspar W Weinberger on 3 December 1974, and was lodged within the National Institutes of Health, a subdivision of the Department, under the chairmanship of Dr Kenneth Ryan, head of obstetrics and gynecology at Harvard Medical School.

Most of the topics assigned by the National Research Act to the Commission dealt with experiments on humans; in particular, the Commission was instructed to prepare a report within four months on the subject of fetal experiments, to be followed by other reports on psychosurgery and on various groups of experimental subject, such as prisoners, children, and persons institutionalised as mentally disabled. (In addition, the Commission was asked to study the social implications of developments in biomedical research, a rather open-ended topic on which the Commission made little headway compared to its thorough treatment of the topics centrally related to experiments on humans.) To draw together its work and provide guidance to IRBs the Commission also prepared a brief summary report – called the ‘Belmont Report’ after the federal meeting centre at which its conclusions were first debated – in which it set forth several basic principles of bioethics on which it had attempted to base its conclusions.

The staff of the National Commission was a mixed group: some career civil servants, mostly from DHEW, and some outside experts from academic medicine and ethics. In addition, consultants from a wide variety of fields were commissioned to write advisory papers. The Commission held open monthly meetings which included an opportunity for public testimony. In some ways the National Commission seems similar to what I know of the Comité National Consultatif d’Ethique, although the French group has only one annual open meeting, includes government officials, and is much larger in size, consisting of about 35 people.

#### *Broad-based standing bodies*

As the National Commission was completing its statutory mandate in 1978, Senator Kennedy recommended raising it to the level of a Presidential Commission to look at issues in

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human research across the entire federal government. In the House of Representatives, however, the view arose that any successive commission should have a broader mandate, encompassing issues in medical practice as well as in research on human subjects. Through the agreements reached by Senator Kennedy and Representative Paul Rogers, Chairman of the House Health Subcommittee, a provision was attached to a statute passed in 1978 authorising the creation of the President's Commission.<sup>5</sup>

I will use this group to illustrate my third type of governmental bioethics committee. The mandate of such a group is general in nature including potentially all topics in bioethics. The President's Commission was required by its statute to conduct studies of a number of topics – including access to health care, informed consent in treatment as well as in research, genetic screening and counselling, and the definition of death – but the topics could be increased at the request of the President. (President Jimmy Carter, through his Science Advisor, Dr Frank Press, did add a topic – human genetic engineering – to the Commission's mandate.) The topics could also be increased at the option of the Commission itself, and this course was also followed when the Commission chose to add the topic of foregoing life sustaining treatment to its list of studies.

What are the salient characteristics of this third type of commission? Like the National Commission, the President's Commission consisted of eleven members from law, ethics and public affairs, under the chairmanship of Morris B Abrams, a New York lawyer and former President of Brandeis University. Unlike the National Commission, the President's Commission was conceived as a permanent body whose members would serve in groups with staggered terms. Since the Commissioners were not named by the President until the summer of 1979 (and were not sworn in until January 1980), the terms served by the first group of Commissioners expired two years later in the summer of 1981. By the conclusion of the Commission's work, eight of the eleven members were appointees of President Ronald Reagan.

Although the Commission was established in a fashion that contemplated a continuing life (as, for example, the

limitation of service to two consecutive four-year terms for any Commissioner), the inclusion of a 'sunset clause' meant that the Commission was scheduled to go out of business in December 1982. The purpose of this clause was to allow the legislature to review the group's work and then, by a simple action, to extend its work.<sup>6</sup> Despite the termination date, I still believe that it makes sense to describe such groups as 'standing committees', both because their lives are of indefinite duration (if the termination date is postponed) and because during the three or four years that the President's Commission functioned, it felt free to range quite widely within the field of bioethics. It is true, nonetheless, that the termination date – with the deadlines it imposed for the completion of reports – was an effective, if somewhat oppressive stimulus for Commissioners and staff alike. It might well be that without this goad, some of the intensity that characterised the Commission would have been lacking. The limited time period also made it sensible to bring in staff from outside government, while a truly permanent body might be more heavily staffed by career civil servants. This is not to condemn such a body as a hopeless bureaucracy, but it has been my experience, especially when part of the subject under scrutiny is the performance of the government itself (as it was in our work), that outsiders are more likely to take a fresh look at an issue and are less likely to temper their findings and recommendations out of a need to be gentle with their fellow civil servants.

Like the National Commission, the President's Commission had to 'do ethics in public', because its work was governed by the Federal Advisory Committee Act which requires that such groups hold their meetings in public unless they make a strong case for the need for specific private sessions. Despite the prediction of some people that sensitive subjects of the sort being dealt with by the President's Commission could not usefully be discussed in public (lest there be a great deal of posturing and pointless rhetoric on all sides) the requirement that the meetings were open to the public did not prove an impediment to the effective functioning of the Commission. Indeed, the requirement seems to me to have had mostly salutary effects. All those who spoke, especially Commissioners and staff members, were mindful of the need for responsible

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comments and thoughtful deliberations. Further, the fact that a stenographic record was being made of the proceedings encouraged witnesses to aim for a high degree of accuracy and emphasised the importance of pointed comments rather than rambling dissertations. Finally, the fact that the sessions were public served to underline that the subject matter before the Commission was not esoteric but was a matter of concern and interest to all citizens; and their interest was furthered by the general press coverage of many of the meetings, particularly those at which reports and conclusions were set forth.

Another characteristic of the President's Commission – actually one of the most important – was that the Commission had no power to regulate. Its only real power was that of persuasion. In 1978, philosopher Ruth Macklin told the House Committee holding hearings on the bill that established the President's Commission, that to have any clout, the work of a commission must be 'clear and understandable to a concerned public as well as satisfying to those of us who work professionally in the field of biomedical ethics and health policy'. Therefore, the Commission made its minutes widely available to thousands of people across the country who requested to be on its mailing list, and members of the Commission and its staff testified frequently before congressional committees holding hearings on topics germane to the Commission's work and held briefings for Congressional members and their staff. One measure of the effectiveness of the Commission was the frequency with which it was asked to present its work to legislative bodies, as well as the number of times its reports received front-page coverage in the newspapers and were featured on the major news and discussion programmes on radio and television.

Because of the need to persuade, there was a strong drive toward consensus, since a divided body would be unlikely to find its conclusions well respected. Although this may not seem remarkable, it should be remembered that in the eyes of many people the field of bioethics is regarded as highly polarised and subject to political polemics. Yet the only major topic that the Commission chose to avoid was abortion, on which its opinions had not been sought and on which it could add little to the already well-developed medical and ethical

arguments on both sides. Otherwise, the Commission tackled many difficult issues. Rather than leading to timid reports, however, the search for consensus actually pushed the Commission's reports further and made them more influential. The Commissioners worked inductively from specific examples to general principles; that is, they moved outward from a common core of agreement to the point where agreement was no longer possible. This form of deliberation helped to show that the sphere of consensus was quite large.

#### *Action-oriented panels*

Let me briefly describe the fourth type of governmental group on medical ethics with which we have had experience in the United States, namely a standing body with direct involvement in binding decisions. As a result of the work of the National Commission, new regulations were issued by what is now known as the Department of Health and Human Services in 1978. Among the provisions of these regulations was the requirement that research involving certain highly sensitive groups be approved at a national level by an Ethics Advisory Board (EAB) appointed by the Secretary as well as review and approval by the IRB of the institution at which the research is to be conducted.

The Secretary of the Department of Health, Education, and Welfare, Joseph Califano, established an EAB in 1978. Its first task was to review the acceptability of *in vitro* fertilisation (IVF) because of a protocol submitted by Dr Pierre Soupart of Vanderbilt University. After one year of hearings and commissioned papers, the EAB issued a report in May 1979 recommending that the Secretary permit research on embryos up to two weeks after fertilisation in the laboratory, provided there was to be no implantation of the embryo thereafter.<sup>7</sup> That report has sat on the table for the past eight years without having a definitive response from Secretary Califano or any of his successors, and, ironically, Dr Soupart has since died while waiting for action by the federal government. With the onset of the President's Commission, the EAB was dissolved. Although the President's Commission and EAB had different functions, with no necessary overlap, the EAB did not have the necessary bureaucratic support to continue.

### Structure, functions, and accomplishments of the President's Commission

I will now examine the work of the President's Commission from January 1980, when the Commissioners were sworn in, to the issuing of the final reports of the Commission in March 1983. Having served throughout as the Commission's Executive Director, I am not an objective observer, but I hope that my description is accurate enough to provide a basis for evaluating the general utility of such a body that falls into the third category I have described – a standing panel with a broad mandate in bioethics.

The work of the President's Commission was carried out by a staff of about 25 people, mostly professionals, with a small support staff. The Commission was housed independently of any government department or agency and was not part of a standing bureaucracy. Most members of the support staff and one senior professional came from careers in government service but all the rest of the staff were outsiders to government. For example, I took leave from the University of Pennsylvania to run the Commission, and other senior staff members, who included a physician, two of the lawyers, two sociologists, an expert in public health, one economist and a succession of philosophers, plus various research assistants, were drawn from academic settings. The Commission met monthly. During the first several years of its work these meetings took the form primarily of hearings at which experts and other interested parties testified on particular topics that were under study by the Commission and were questioned by the Commissioners and senior staff members. Furthermore, the Commission staff themselves were sometimes in the witness chair, to engage in a dialogue with the Commissioners and attempt to convey the results of their studies and to learn from the Commissioners, in general form, the directions that should be taken by the Commission's reports. Although many of the witnesses were invited – and included the consultants who were writing papers for the Commission – time was always allotted for other experts and members of the general public who wished to appear and make statements.

After the initial phase during which background was

provided to the Commissioners, the primary work of the staff was to prepare drafts of the Commission's reports. After these had been reviewed by the Commissioners they were rewritten by the staff. Commissioners who had special expertise in an area under study took a more active hand in the process of revision of these reports. In the end, there was unanimity on all the Commission's ten reports except one, on which there was one dissent. In addition to the ten reports there was one report of the Commission's work in commissioning papers and convening a workshop on *Whistleblowing in Biomedical Research*. The reports were released as finished; the work amounted to 16 volumes because the background papers were published as separate appendix volumes for some of the reports.

Rather than review all of these, I will characterise the results in four ways: (1) laying to rest, (2) the crucible, (3) the watchdog, and (4) the small rock (sometimes called the lightning rod or, less charitably, the dumping ground) but I prefer to think of this last role in Homer's terms when in *The Odyssey*, he says 'a small rock holds back a great wave'.

#### *Laying to rest*

The first category is probably best illustrated by the first report the Commission issued in July 1981 on the 'definition' of death. This topic had been a matter of public concern since December 1967 when Dr Christiaan Barnard performed the first human-to-human heart transplant. In 1968 an ad hoc committee at the Harvard Medical School promulgated criteria for diagnosing death in comatose bodies whose breathing was being artificially maintained. By 1980 when the President's Commission began, many states had laws recognising criteria of the type promulgated by the Harvard Committee and there was general medical agreement although no up-to-date guidelines had been agreed upon.

Given the fact that the subject was already well advanced, it seemed to the Commission that the major impediment to its mandate – to consider the advisability of legislation on the subject – was the very multiplicity of statutory proposals that had been made by groups such as the American Medical

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Association, the American Bar Association, and the National Conference of Commissioners on Uniform State Laws. Most of the legislative 'definitions' had been adopted by states in the early 1970s, but the process had slowed to a trickle, and the few that were legislating tended to write their own bills (with all the confusion and imprecision one would expect) rather than choose among the competing laws. Therefore, the Commission concluded that the best way to avoid simply adding to the multiplicity of proposals was to develop a proposal on which all the major proponents could agree. The result was the Uniform Determination of Death Act (UDDA) which was endorsed by the AMA, the ABA and the NCCUSL, as well as the Commission, when its report *Defining Death* was issued in July 1981. The UDDA has since become law in many states. It recognises that death occurs when there is a total and irreversible cessation of circulatory and respiratory functions, or a total and irreversible cessation of all functions of the brain including the brain stem. Equally important to the provision of a statute was the drafting of a set of medical guidelines by a group of the leading medical experts convened by the Commission. When these guidelines were published in the *Journal of the American Medical Association* they were hailed as a landmark,<sup>8</sup> and today they provide a reliable statement on medical techniques for determining that death has occurred either on cardiopulmonary or neurological grounds.

To summarise, the 'laying to rest' function of a commission seems to be to develop recommendations for action, in this case for legislation and for professional action, and to bring together a broad coalition of people in the field to insure that the recommendations will be so broadly accepted that the topic will no longer be a matter of division or contention.

#### *The crucible*

I refer to the second category as that of the crucible, thinking of it as a place for publicly grinding out conclusions on controversial issues when a consensus is not yet apparent. In the case of the President's Commission, three of its reports probably fall into this category: the one on informed consent, *Making Health Care Decisions*; on 'pulling the plug', *Deciding to*

*Forego Life-Sustaining Treatment*; and on equitable access to health care, *Securing Access to Health Care*. These are all topics which had been approached by divergent groups in the previous decade. The Commission's role here was threefold. First, it had to identify those elements underlying the apparently disparate views expressed in previous discussions. Second, it had to correct misunderstandings or errors, particularly as those were responsible for the divisions in the public debates; and finally, it had to articulate the implications for public policy and ethical behaviour in a way that would be broadly acceptable. Plainly these objectives involved the Commission in processes of analysis and synthesis; as such it required more original scholarship than the first ('laying to rest') function because there was less existing agreement. These topics did not in the view of the Commission always lead to recommendations for legislation. In some cases the objective of the Commission was to frame the thinking on the subject of public officials, such as judges and legislators, and to attempt to push the academic experts forward so that the Commission's findings and recommendations could become the starting point for future discussions. This would reduce some of the jagged pieces that had prevented public understanding and the advancement of conclusions.

A good example of this second category was the work of the Commission on patient autonomy, and the necessity for and the means for its preservation in the face of patient incompetence contained in the reports on making health-care decisions and on deciding to forego life-sustaining treatment. These conclusions have been widely influential. For example, in the past year a California Appellate court and the Supreme Court in 'landmark opinions' have placed heavy reliance on the report, *Deciding to Forego Life-Sustaining Treatment*. The weight accorded to this report illustrates that those who perform ethical and social analysis need a clear understanding of the realities of the practice they are scrutinising. Such an understanding was provided for the Commission by its members, its staff and expert consultants who all insisted that the realities be well attended to rather than solely being concerned with ethical or philosophical discourse. A great deal of effort was placed on the clarification of facts as they

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illuminate issues, such as 'active' versus 'passive' euthanasia – something that can become a matter of heated, but nonetheless rather abstract, discussion until it is grounded in understanding of the realities of hospital practices and nursing home procedures, the means of dealing with pain, and the psychology of physicians and nurses.

#### *Watchdog*

The third function of the Commission is well illustrated by its work in the area of federal regulation of human subject research.<sup>9</sup> This is a topic that had been thoroughly studied by our predecessor, the National Commission for the Protection of Human Subjects. The Commission therefore placed particular emphasis on the portion of its mandate to report biennially on the adequacy and uniformity of the federal oversight of research conducted or funded by the government. Although this was perhaps the least exciting topic assigned to the President's Commission, it was very important for several reasons. First, the government's efforts in this area are plainly a matter of great public concern; indeed, the whole process of governmental commissions and study panels in biomedical ethics was begun because of what was perceived as abuses of human subjects in research. Second, since the National Commission had gone out of existence there was a strong possibility that some of its conclusions and recommendations would simply fall between the cracks of the federal bureaucracy if the President's Commission did not vigilantly monitor the response of federal agencies. Third, the National Commission had primarily studied the work of what is now the Department of Health and Human Services, the largest sponsor of research with human subjects, but the President's Commission had a broader mandate. It was to examine research issues throughout the federal government, and one of the principal recommendations in this area in the first biennial report on research in 1981 was that the government should adopt a single set of regulatory requirements for all federally sponsored human subject research to simplify the burdens placed on researchers and the local IRBs.

*A small rock*

The final function that a standing ethics group can serve is illustrated, I believe, by the work of the President's Commission on a very controversial topic – namely, genetic engineering. In 1980, shortly after the Commission began its work, leaders of the Catholic, Protestant, and Jewish congregations in the United States voiced cries of alarm over the prospect that genetic engineering techniques would be soon extended to human beings. Their concerns, which were addressed to President Carter, led his science advisor to request that the President's Commission add the subject of human genetic engineering to its mandate.

In its report, *Splicing Life*, the Commission took a scientific and a philosophical and religious view of the topic. It attempted to place the concerns in historical context and to show that many forms of manipulation of the genetic basis of human disease were no different from conventional, accepted treatment. But treatment that went beyond the somatic cells to alter the human germ line cells raised moral as well as medical concerns. By the time the Commission had completed its work, a number of newspaper reporters had become interested enough in the topic to write thoughtfully about it for their publications, and the Commission's conclusions were greeted with general support by editorial writers. In three days of Congressional hearings, when the report was issued in November 1982, the conclusions of the Commission were accepted by a wide variety of scientific and ethical experts and by representatives of the religious groups that had initially provoked the study.<sup>10</sup>

Is a commission on medical ethics desirable?

Doubts have been expressed in the United States and in the United Kingdom about whether a commission on medical ethics is desirable, and a basic concern is whether the whole field of medical ethics can be covered. Yes, it seems to me it can – piece by piece. The fact that the broad field is taken as the mandate for the group means that throughout its work it is likely to look for common themes. In the United States we

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tend to describe the field as that of 'bioethics', precisely to emphasise that more is at stake here than simply medical ethics (in other words, the conscience of the physician faced with dilemmas). The analysis of this area of public policy seems to be helped by a realisation of the breadth of the concerns, lest the particularities – as important as they are – lead the group to attempt to become 'too expert' at the cost of perceiving the points of gravest importance to the general public rather than merely to experts. Nonetheless, I think it is important to emphasise, at least in the case of the President's Commission, that there was no thought of setting out to pronounce abstract philosophy. Such common principles and themes as emerged did so very much from the specific questions and concrete conclusions that the Commissioners reached on their particular topics. This approach also avoids ideological clashes interfering with analysis of specific issues and facts, though in the end it does not suppose that the Commissioners will be *tabulae rasa* when the time comes to reach final conclusions.

Second, one may ask whether there is any advantage in having a standing panel. Again, I believe the answer is yes. The breadth of inquiry already noted offers an opportunity to increase the legitimacy of the group if it operates as a continuing body constantly building its credibility from one study to the next. In the case of the President's Commission, it consciously chose the topic of determining death as its first report because it seemed likely at the outset that a report could be produced which would be broadly accepted and would establish the Commission as a group that did good work.

Third, the question arises as to the audience such a standing group should address. When a group is charged to study only one issue it seems to me more likely that its focus will be on the appointing agency. But for topics in bioethics I think that is a mistake. The issues are difficult, but they are not arcane. In a democracy, the public must be involved in the resolution of these issues and, therefore, these are issues about which the public should be educated. Interestingly, the notion of a standing group addressing such issues, building on the work of the President's Commission, has now been carried on in the United States through a grass roots movement at state and local level. Several states, such as New York and New Jersey, have

governmental commissions on bioethics made up of members of the public and state officials as well as the usual interdisciplinary group of lawyers, physicians, and ethicists. Even more remarkable are the groups organised by citizens in which meetings are held in homes, churches and schools to address topics such as life sustaining treatment and access to health care, often leading then to statewide 'health care parliaments'. This process, begun in 1983 by a group known as Oregon Health Decisions, and now in operation in more than a dozen states, reminds us of the broad appeal of these issues and of the fact that any continuing body needs to address the issues at a level that is meaningful to members of the public and not simply to experts or to government officials.

All this activity may well raise one final concern: is it really desirable to have the government so deeply involved in these matters? After all, many of the questions raised touch on the most personal and private aspects of life, aspects that in the United States enjoy explicit (as in the First Amendment) or implicit (as in the constitutional 'right of privacy') protection from government intrusion. This seems, however, more an objection to the way in which a commission approaches its task rather than to the existence of a commission. Particularly for a body without rule-making authority, there need be no necessary implication that assigning a topic to a commission means that the topic is regarded as fair game for official intervention, whether to promote the interests of the state or the 'best interests' of the public. Furthermore, many of the topics – such as treatment termination – are already entwined in the state and its laws, and a major function of a commission can be to extricate individuals from excessive legal involvement. A commission can reassure people that the law on certain points is clear (and thus, there is no need for resort to court for a judicial imprimatur on a proposed course of action about which the parties do not actually disagree), or it can show the ways in which the law should develop, better to serve important values. The President's Commission placed a great deal of emphasis on this task, and almost none on 'law-making' in the more conventional sense. (It recommended only one statute – the UDDA – and in the regulatory sphere urged reduction in the number and complexity of federal rules on

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human research.) The Commission's primary concern was with presenting ethical theory and practical advice (about physician-patient interactions, for example) in ways that promoted thought and conversation among all people – researchers, physicians, nurses, patients, family members, legislators, judges, and administrators. Activity of this sort need raise no concern about 'Big Brother'.

Thus, at a time when there are many perplexing issues generated by biomedical research and practice, our experience in the United States over the past decade is that there can be great benefit for all concerned in establishing a commission with a broad mandate in bioethics to examine the field and share its reflections, with as much unanimity as possible, with the public.

#### Notes and references

- 1 See, for example, US Bureau of the Budget. Report of the Committee on Chronic Kidney Disease, 1967; US Department of Health, Education, and Welfare, National Heart Institute, Ad Hoc Task Force on Cardiac Replacement. Cardiac replacement: medical, ethical, psychological and economic implications, 1969; US Department of Health, Education, and Welfare, National Heart and Lung Institute, Artificial Heart Assessment Panel. The totally implantable artificial heart: legal, social, ethical, medical, economic and psychological implications, 1973.
- 2 US Department of Health, Education, and Welfare, Tuskegee Syphilis Study Ad Hoc Advisory Panel. Final report, 1973.
- 3 Katz. Yale Law Report, 20, 23, Spring 1986: 'During our deliberations, we had, of course, repeatedly asked the staff members assigned by HEW – and a number of them were knowledgeable senior officials – to locate the original documents. They assured us again and again that they had tried but could not find them. I believe now that this was a cover-up. *J'accuse* – they must have known.'
- 4 National Research Act, Title III, Public Law 93-348, 88 Stat 342, 1974.
- 5 President's Commission, Title III, Public Law 95-622, 1978, codified at 42 USC Ch 6A.

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- 6 In the autumn of 1982, Senator Kennedy proposed a two-year extension of the President's Commission; when this became entangled in other debates in the Congress, a three-month extension was adopted on 20 December 1982 in Public Law 97-377 which amended the 'sunset' date of 31 December 1982 to 31 March 1983.
- 7 US Department of Health, Education, and Welfare, Ethics Advisory Board. Report and conclusions: HEW support of research involving human in vitro fertilization and embryo transfer, 1979.
- 8 Barclay. Guidelines for the determination of death. *Journal of the American Medical Association*, 246, 2194, 1981.
- 9 US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Protecting human subjects: the adequacy and uniformity of federal rules and their implementation, 1981; US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Implementing human research regulations: the adequacy and uniformity of federal rules and of their implementation, 1983. In addition, at the urging of the Secretary of the HEW and with the support of the soon-to-be-disbanded EAB to which the topic had originally been assigned, the Commission also prepared a report, Compensating for research injuries: the ethical and legal implications of programs to redress injured subjects, 1982.
- 10 Human genetic engineering: hearings before the subcommittee on investigation and oversight of the Commission on Science and Technology, 97th Congress, 2nd session, 1982.

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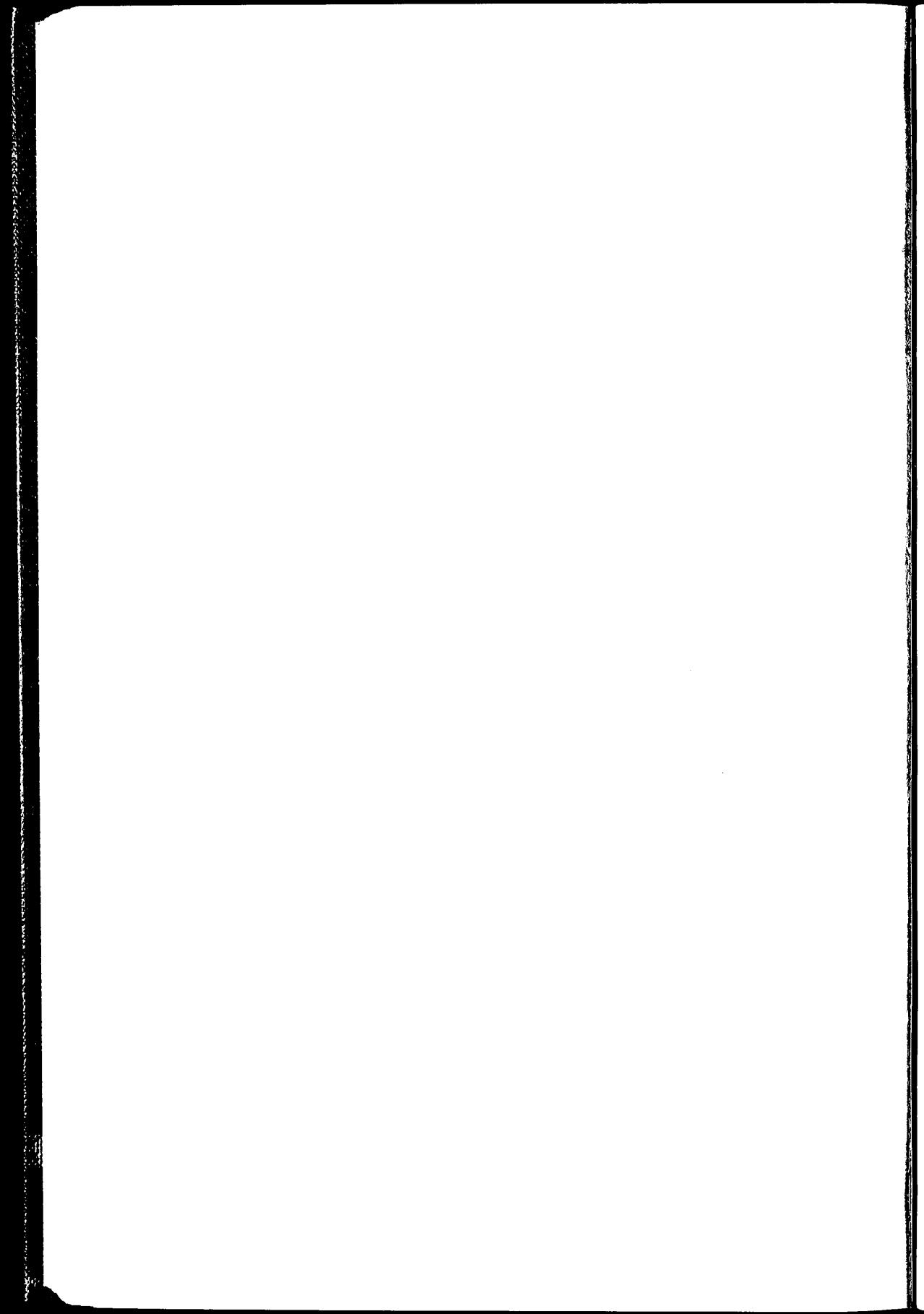
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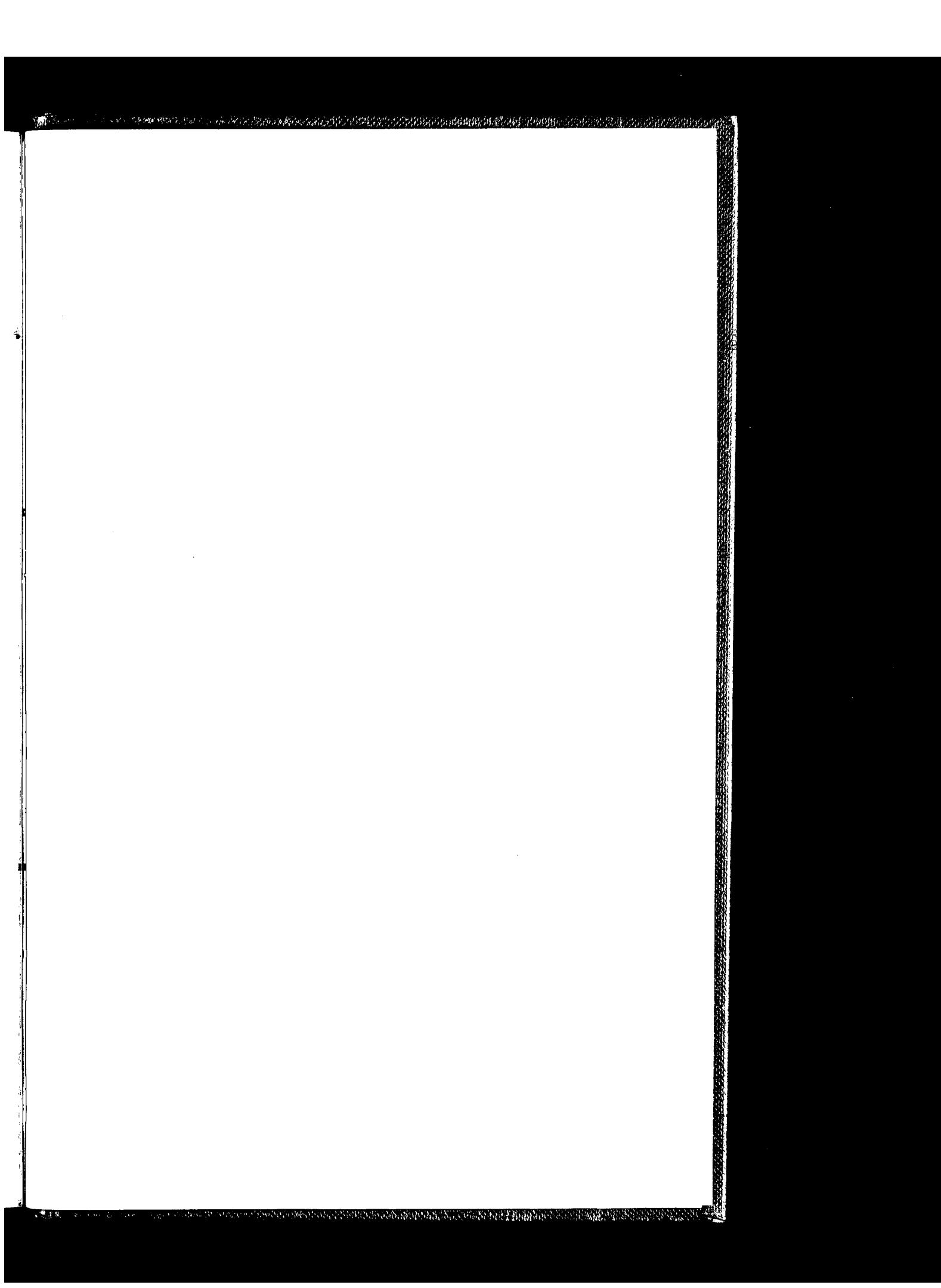
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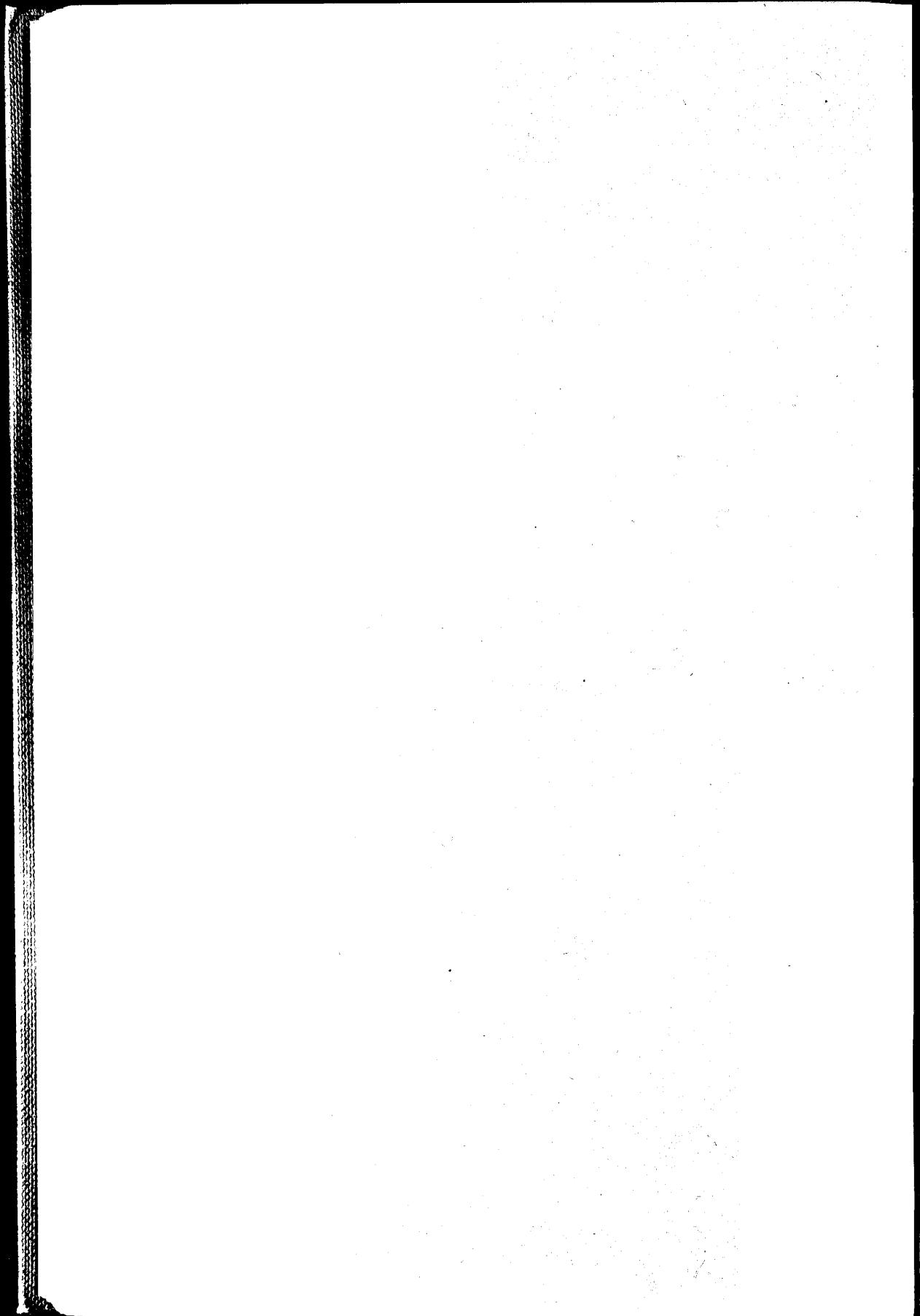
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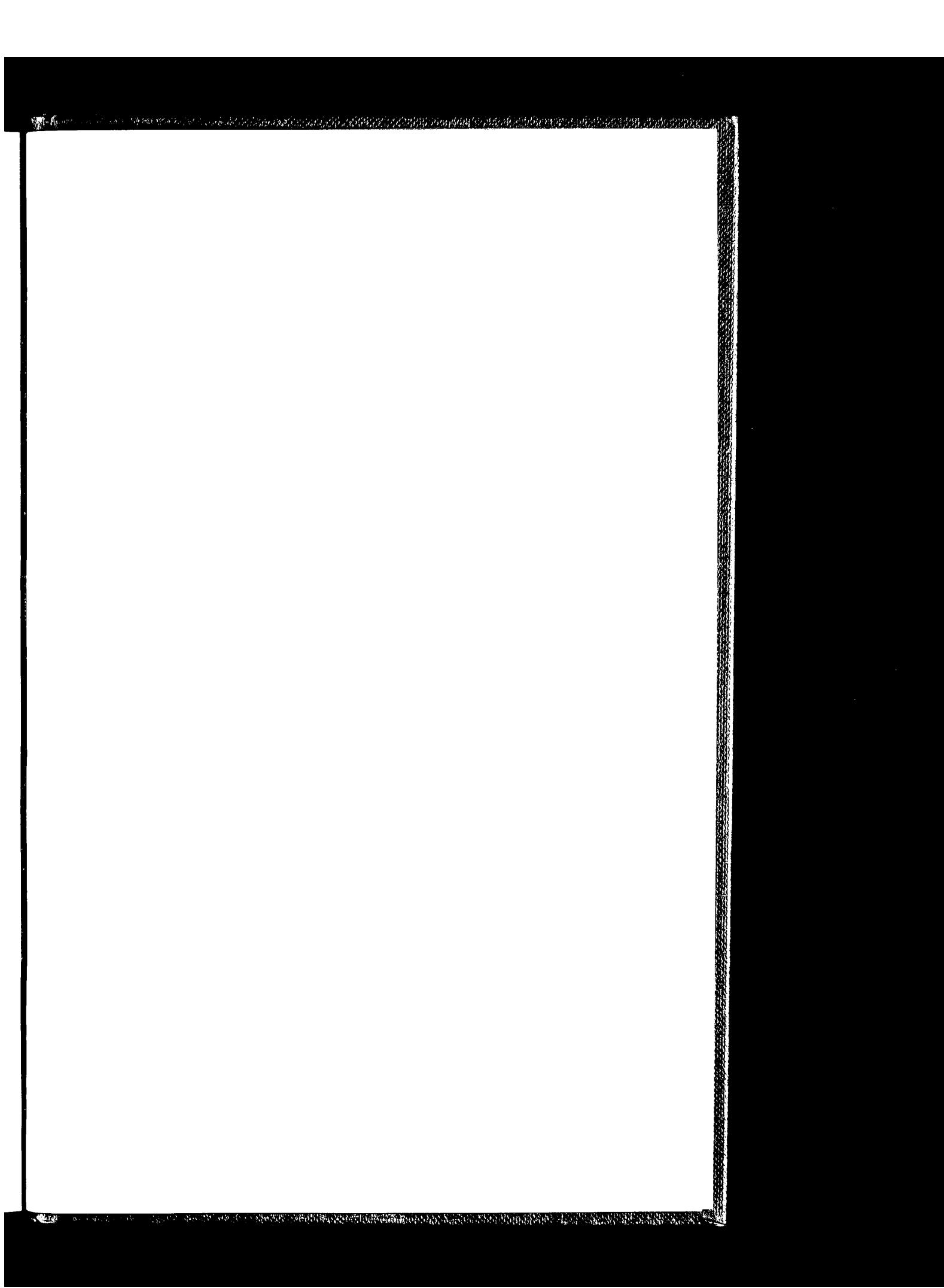
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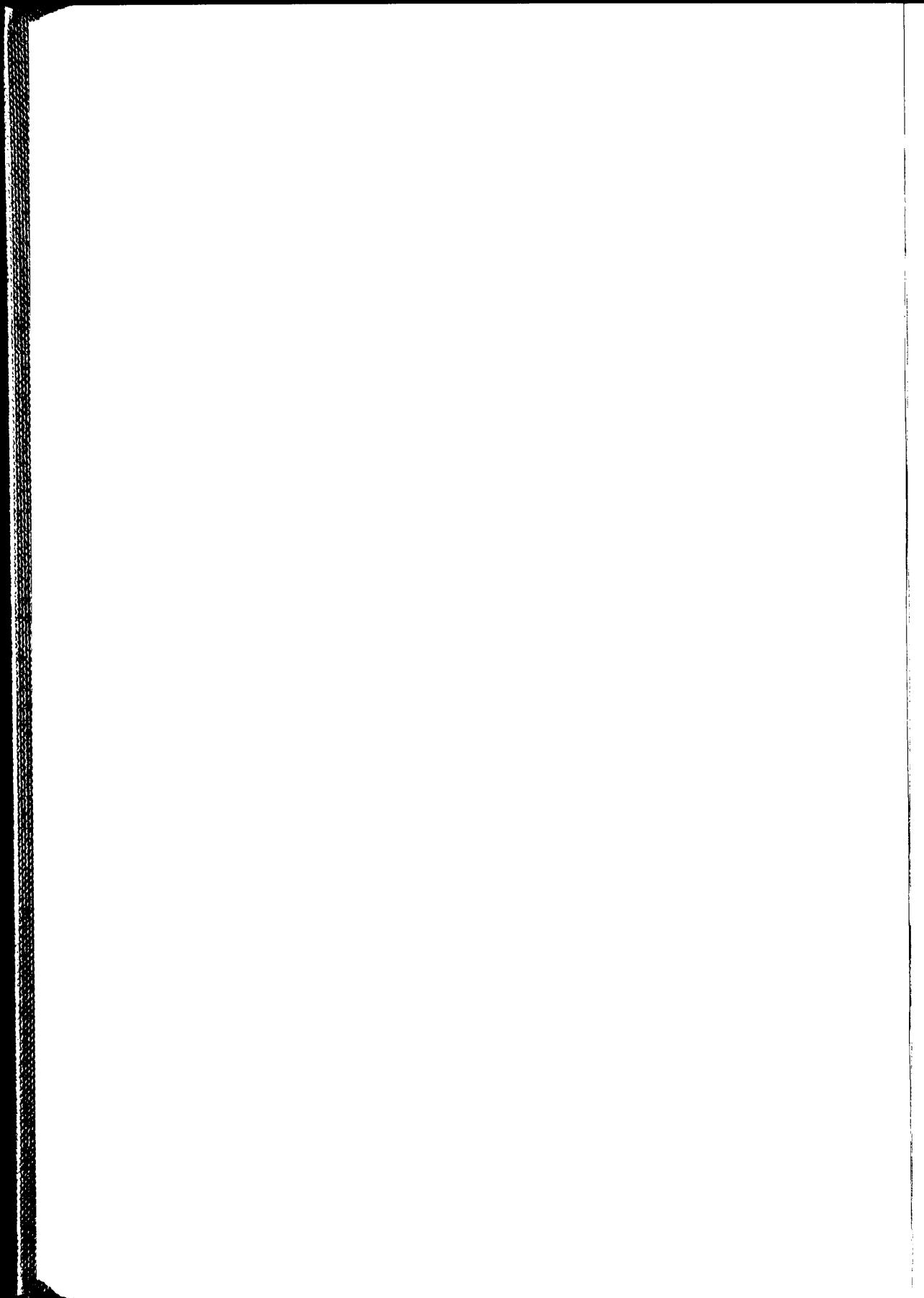
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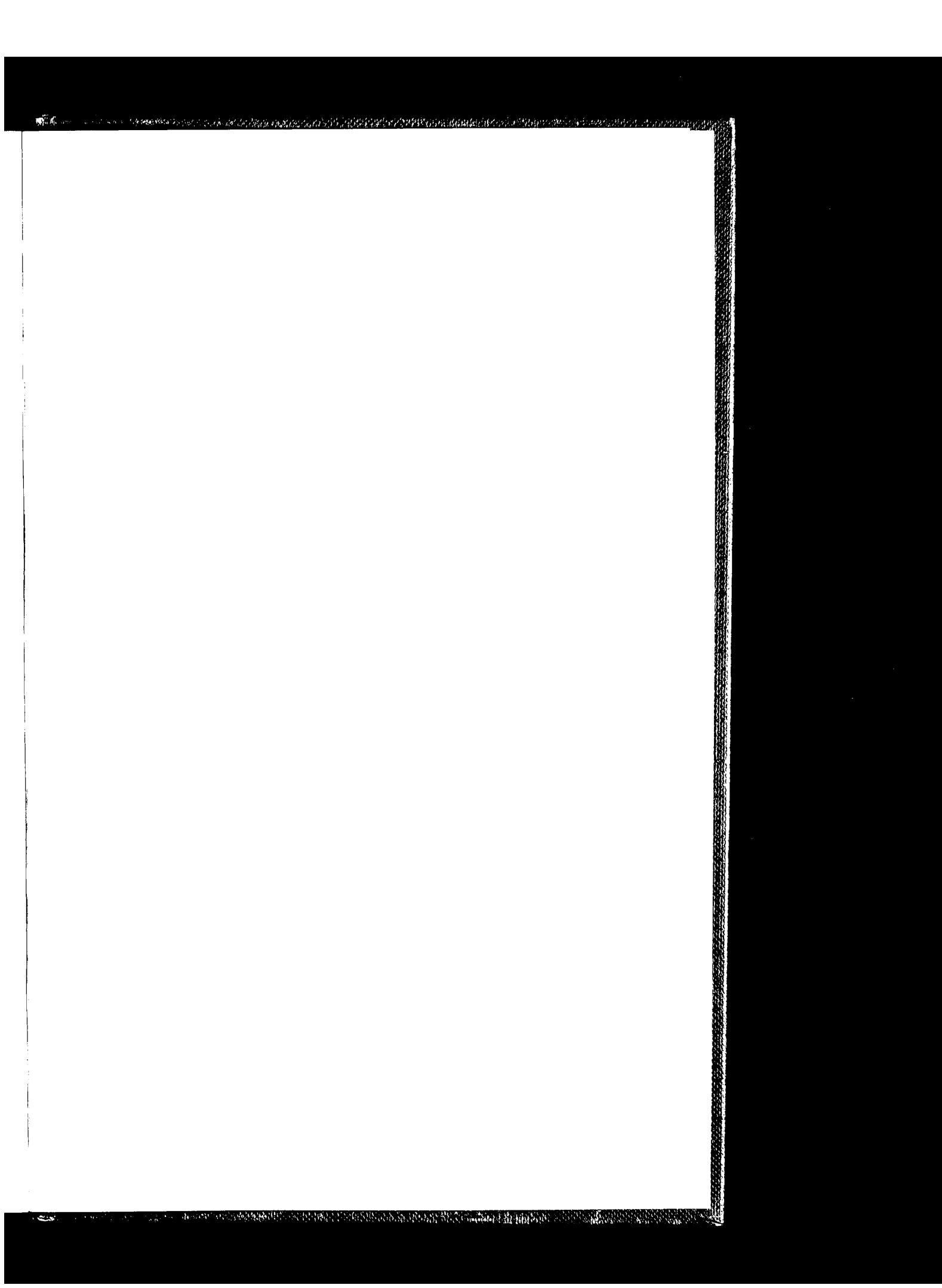


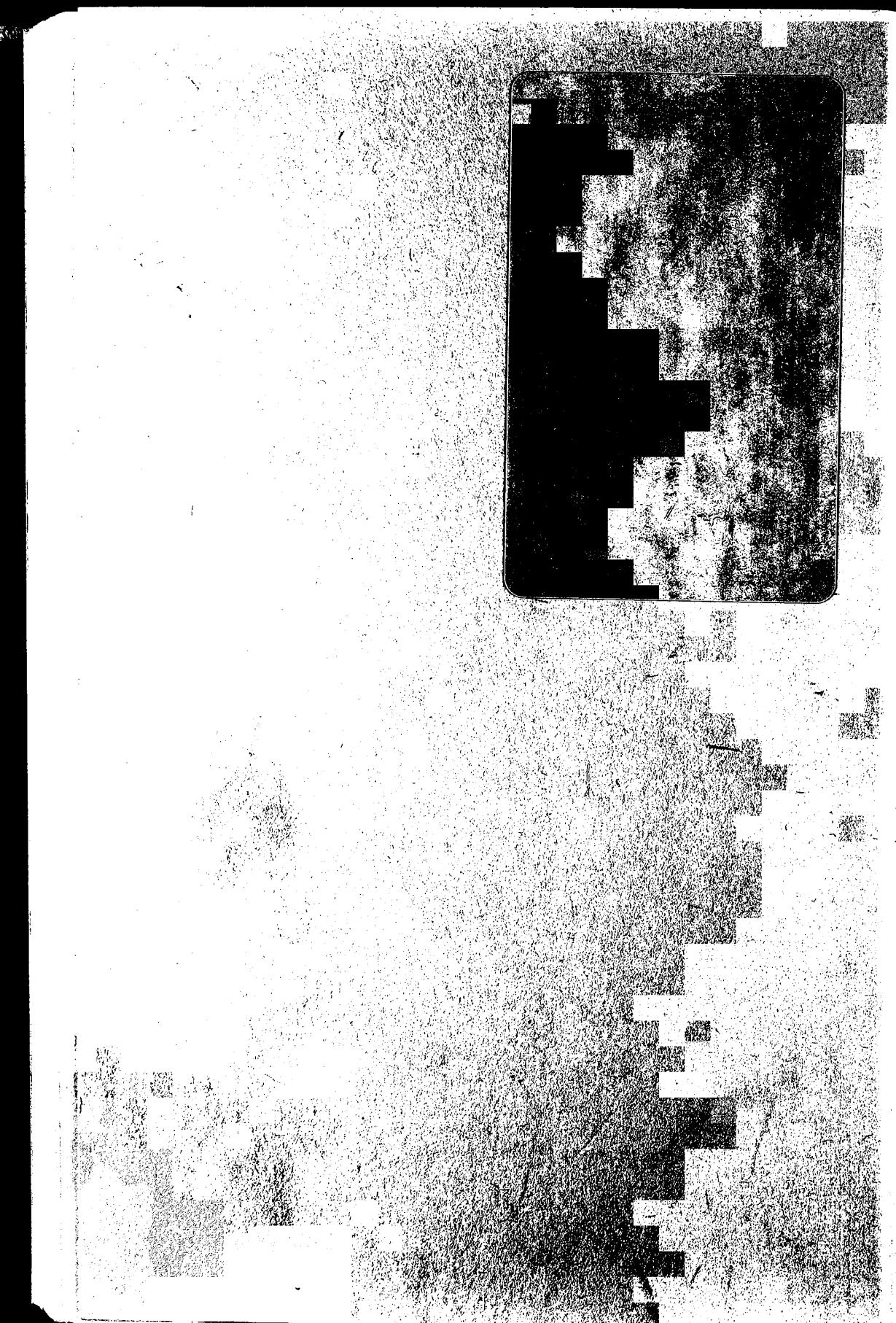












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## KING'S COLLEGE STUDIES IN MEDICAL LAW AND ETHICS

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