The politicisation of medical ethics

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There was a time when medical ethics was a matter of professional behaviour, a code of conduct upon which the public relied, but with which they need not otherwise concern themselves. The code for doctors involved confidentiality, always intervening with the best interest of the patient in mind, and such concepts as were thought to be incorporated in the Hippocratic Oath. Without the exercise of such virtuous practices, there could exist no trust between doctor and patient, and it was widely accepted that the relationship between them depended on trust.

Trust between doctor and patient is even more important today than it used to be, particularly since for patients in the NHS there is a growing fear that their treatment will be dictated by financial considerations as much as need. But the cultivation of these virtues is now only a small part of what we think of as medical ethics, because of the new complexity of the subject created by advances in science. Public demands for treatment have increased enormously, stimulated by the public’s impression that the range of successful therapeutic interventions is constantly expanding. Moral or ethical questions about medicine in general, rather than about individual doctors, have increasingly entered the public domain. Is medicine doing what it should do? Are there some discoveries in medical science which should not be translated into medical practice? Rather than members of the medical profession being subject only to ethical guidelines, or professional codes, is it the case that medicine as a whole should be subject to regulation from outside, even to restrictive legislation? Thus politics has entered medical ethics. By ‘politics’ I mean questions of public policy which merit public discussion, and therefore, because we are a democratic society, ultimate discussion in parliament.

Ethics and genetic manipulation

The expressions ‘genetic engineering’ and ‘genetic manipulation’ sound terrible to the general public and both are likely to produce the routine, and to me very irritating, reaction that scientists are ‘playing God’, and must be brought under political control. But, irritating though this particular turn of phrase may be, there is a real question here. To what extent are we, as a society, content to leave medicine to the medically qualified? Should we think rather of a consensus of moral opinions among all who are involved (and that is everyone, as we are all potential patients)? I believe that it is the duty of scientists, doctors, politicians and the press to work together as far as possible, and to try to understand, sympathetically and truthfully, the kind of public panic which seems to arise at the thought of genetic medicine. It would be desirable to persuade people that genetic manipulation, though highly complex, is not particularly mysterious. It would be useful to get people to prepare themselves for advances in technology, and to be ready to see gene therapy, whether direct or through the use of drugs, as just another form of therapy. On the other hand, it is futile to adopt the breezy utilitarianism of some philosophers who write in this field.

What lies at the root of public fear and suspicion? In 1984, the philosopher Jonathan Glover published a book whose title, What sort of people should there be?, gives us a clue. The title alone immediately suggests that such a question should not be answered, or perhaps even raised, by scientists or doctors. Why should the question arouse such fear in a medical context when it might equally be raised in an educational context without producing so violent a reaction? We may subscribe to the view that we would like the world to be full of intelligent, imaginative, critical yet tolerant people and strive to increase their numbers by teaching them these values. Hardly an eyebrow would be raised. Why, then, are we so horrified at the suggestion that one day genetic manipulation might perform this function?

The answer lies somewhere in the deep fear we have of the loss of freedom implied in the word ‘manipulation’. We profoundly dislike the idea of being controlled by someone who sets up to know better than us, and who brings it about that we shall be as they say we should be, even if this would make us more useful or happy. Hardly anyone would accept the suggestion that, if a miracle chemical were found that would make everyone happy, or even industrious, with no apparently harmful side effect, this drug should be incorporated, like fluoride, into the water supply. Education can try to mould people of the kind that society would like, but it can do no more than try. Education enables people to decide whether or not they accept the model held up for their admiration by their teachers. They can rebel, or, if they do not, they can interpret and reinterpret the ideal according to their own vision of society. They can suggest new goals for themselves which, perhaps, no one else had thought of. Indeed, the ability to do this is a uniquely human capacity and one that we value above all else.
It is the threat to autonomy, then: to setting our own goals and pursuing our own ideals, which lies at the root of the fear and suspicion people experience when they think of genetic manipulation. They think not so much of the manipulation of genes, as the manipulation of people. For they have come to believe in what is, in effect, the modern myth: that we are wholly determined by our genes and that genes themselves are computers – sources of chemical information. The Mad Scientist whom we all used to fear was a physicist: he would succeed in blowing up the world and that would be the end of us. In the new demonology, the Mad Scientist has become a biologist. There is a very proper horror of being controlled by this madman or, still worse, by his political masters. Big Brother might be found standing behind the research biological scientist or the doctor. He could dictate what people there should be by the compulsory screening of fetuses and compulsory abortion of the unsuitable, or, when such things become possible, by direct intervention to change their genes, and cloning of approved adults. Indeed, since 1997 the fears of many people have centered on human cloning. Such fears bring the ethics of medicine into the public arena where journalists and politicians must declare their opinions, and where legislators may be urged to get to work.

**Politisation**

At present, while the abortion of seriously defective fetuses is a reality (though Big Brother cannot dictate it, and parental consent is mandatory), the genetic manipulation of the fetus, or gene therapy, is still in the future. This constitutes one of the great difficulties for politicians, whether they are seeking to reassure the public or to devise ways of regulating the medical profession. One may raise the question whether, when considering the uses or abuses of the new genetic knowledge daily being added to the store of existing knowledge, it would not be better to confine ourselves to the consideration of what is possible at this time and leave imaginative projections into the future to the writers of science fiction. It is not, after all, simply the techniques for changing people's personalities or their abilities that are missing: the actual concepts are not clear either. We do not have any idea which genes or sequences of different genes are responsible for intelligence, or imaginative creativity, or proneness to hard work. We have little exact idea of the effect of different environments on genetic patterns of these kinds. Nor are we even sure what is meant by 'intelligence' or 'creativity', nor how to identify them when we think we have found them.

Surely then, with so much still unclear, there is a great deal to be said for abandoning all discussion of making people the way we want them – of what is usually meant by 'eugenics'. People will continue, no doubt, to discuss such matters in private, just as they will continue to discuss the possibilities of cloning particularly admirable people; but there is no need to allow them to be discussed as matters of public policy in the political domain. It is vastly premature to start thinking of the political regulation of something that is, so far, impossible to achieve. After all, President Clinton's instant reaction to the birth of a sheep cloned from an adult cell – to place a moratorium on all research into ways of cloning humans – is widely seen to have been too hasty.

The drawback of this solution, however tempting, is first, that it will be only temporary. Second, issues such as genetic manipulation, though they are or will be political in that they may give rise to legislation according to the will of parliament, are essentially moral or ethical issues, and morality must be a matter of principle, not of _ad hoc_ hand-to-mouth expediency. To come to a conclusion on a principle, it is necessary to consider what you would or would not do if the occasion were to arise. In that case you need to know what you would say, or what you might be permitted to do, if a highly desirable characteristic could be produced in people, or a highly undesirable characteristic removed, by a technical intervention that was simple, predictable and the result of replacing one gene. It is not enough simply to say that to do this is technically impossible, for if you think either that you would permit it if it were possible, or that you would not permit it, however desirable the consequences might be, then you have come upon a general moral principle which needs to be first formulated, and then, as far as possible, justified.

The same question may be raised with regard to cloning from human adult cells by nuclear transfer. It does not matter that the example is not a real one. Plato introduced just such a generalising device in _The Republic_, when he raised the question whether, if we were possessed of the ring of Gyges which rendered us invisible, we would all go around committing crimes, knowing that we would never be found out, or whether there is a kind of internal constraint or conscience which would prevent us, independent of the fear of discovery. That Gyges' ring does not exist is irrelevant to this form of argument.

Nevertheless, in spite of the parallel with Plato's form of argument, one has to recognise that when the question is couched not in terms of magic or mythology, but in terms of a possible future world, it must be a matter of caution, balanced realism and common sense if politicians are to formulate an acceptable moral principle with which the public can generally sympathise. They are bound to take some account of how predictable the future situation is when the question of what is or is not to be permitted will urgently present itself. It is for this reason that they must rely on the best possible scientific and medical advice. No one can form a proper moral judgment, nor frame a moral principle, unless they understand to some extent what it is that they need the principle for and what the future facts may be. They must avoid undue haste and the influence of what has come to be known as the 'yuk factor'. They must prepare for such a situation ahead of time, and give thought to balancing obvious benefits, such as the ultimate elimination of certain severe diseases, against possible evils, such as the power that will lie in the hands of those who practise
genetic manipulation. It is because there is a genuine possibility of such manipulation that questions about its rightness or wrongness are practically political, and not merely theoretical or analytic, as Plato’s question was.

However, there can be no sharp or absolute distinction between the kind of question posed by Plato with the help of Gyges’ ring and the questions facing us with regard to genetic manipulation. We, unlike Plato’s readers, need to know what we think is right or wrong about what is being done here and now, but we are aware of the speed of change and development in the field of genetics. It is necessary, therefore, to think ahead; and this means that philosophers and scientists, the practical people, as well as philosophers concerned with theory, must learn to make the best possible use of present knowledge, and to think hypothetically.

There is a fine line to be drawn between a proper prudence with regard to the future and a paralytic refusal to allow research to go on, for fear of hurting down a slippery slope at the foot of which lurk we know not what horrors. The slippery slope argument is often expressed elliptically in the form of the question ‘Where will it end?’ This question has immense appeal to the timorous human imagination, but the argument that prompts the question is not particularly powerful. It is often based not on any specific moral principle, nor on logic, but on a somewhat unflattering (though often justified) view of human nature. The argument runs as follows. There may be a particular and restricted practice, such as the use for laboratory research of human embryos up to fourteen days from their fertilisation, which seems harmless in itself, and whose results are agreed to be beneficial. However, the practice ought to be prohibited by law, not on the grounds that it is harmful or wrong, but on the grounds that it will be abused. (One should note, at this point, that those who think that it is harmful or wrong to use embryos at any stage of their development for research purposes should not make use of the slippery slope argument in this connection. They should stick to advocating that we never get onto the slope in the first place.) The argument relies on the belief that if the first step has been allowed, then inevitably there will be a demand to go on and on, first using early embryos for research, then older fetuses, then babies who have been born, and thence to adults. At this stage the example of Nazi death camps may be invoked. The extension of the scope of permitted research, in our example, is not a consequence of permission having been granted for limited research; nor could the original permission be regarded as a precedent for what is supposed to come after it. However, the extension is thought to be inevitable because of the way people are: always wanting more once their first wish has been granted. The weakness of the argument is that even if it is true that people always want to go further than is permitted, the actual downward slide is not inevitable. It can be halted at any stage by primary legislation, which will criminalise any further step, as happened in the case of embryo research where the fourteen-day limit was imposed by law. Politicians, of all people, should not be too frightened by the slippery slope argument. If they inform themselves, think seriously about what is being done now in the field of genetics, and debate the question whether any legislation is necessary to prohibit anything that is at present practised, then, as new knowledge and new techniques accumulate, they can keep the situation under review. Any further descent down the slope can be blocked by guidelines, regulation, or, if necessary, legislation. What is essential is for them to keep themselves constantly informed by means of a standing committee to review the present and immediate future (a committee which has indeed been set up). The politician’s answer to the question, ‘Where will it end?’ should be, ‘It can end wherever parliament decides.’

There is another dimension to the question of the use of new genetic knowledge which leads to problems far less easy to answer, and this is the international dimension. With the increased possibility of taking out patents to cover new genetic discoveries (or possible discoveries, for even ‘junk’ DNA can be patented), there is also a greater possibility that international companies, especially pharmaceutical companies, will develop genetically engineered drugs and make huge profits. Such international companies cannot be controlled by individual parliaments. The problem of the commercialisation of genetic manipulation is by no means confined to the field of human genetics. It may well be that in the long run there is more to be feared from the developments that are taking place in the genetic engineering of plants and farm animals than in humans. However, this aspect is outside the realm of this paper.

Even with the most impartial and well-informed advice, it will be increasingly difficult to avoid controversy about issues that are more or less immediate, such as the issue of aborting fetuses that are found to carry a faulty gene (Clause 37 (i) (d) of the Embryology Act 1990), or, in the case of pre-implantation as opposed to prenatal diagnosis, the destruction of embryos fertilised in vitro that carry a faulty gene and the implantation of only those that do not carry it. People who are opposed to abortion on any grounds whatever are, of course, a fortiori opposed to abortion on the grounds of a defect of the fetus, and many of those opposed to abortion are also opposed to selective implantation. This is already a fully political issue, insofar as voters in the 1997 election were, for the first time, urged to take into account, when casting their vote, the attitude to abortion expressed by their candidate. Part of the opposition to the ‘closed list’ method of voting for members of the European Parliament came from those who objected to being prevented from voting specifically for people who shared their views on these issues. This means that no MP can any longer wholly disregard constituents breathing down his neck on abortion or related issues, even though such issues have so far always been subject to a free or ‘conscience’ vote. And, apart from those who are opposed to abortion or selective implantation in any circumstances, there is a growing number of people who are hostile to
these practices when carried out on the grounds of a defect in the embryo or fetus.

Genetic screening

Genetic diagnosis was first carried out in the case of pregnancies where there was a high risk of the fetus being affected by an inherited disease. The screening was carried out in the second trimester of pregnancy and the mother was offered an abortion if the fetus was indeed affected. The development of chorionic villus sampling dramatically affected the time in the pregnancy when the screening could be carried out. The danger to the fetus was less, and the abortion, if it took place, was less traumatic. To avoid abortion altogether (and as even those women who are not in principle wholly opposed to it often find it a hard choice to make), the logical next step was to have several embryos fertilised in vitro, and only those that were healthy implanted (or only female embryos, in a case where the risk is solely to male offspring). As the success rate of in vitro fertilisation increases, this option can be seen as the best for embryos that are at risk of carrying faulty genes.

There are two rather different objections to this procedure which are likely to become overtly political issues, if they are not so already. First, as knowledge of the human genome increases, it is thought that more and more people will decide to go in for prenatal screening (or indeed pre-implantation screening) in order to select out any babies which are not 'perfect'. It is unlikely that the genes for such qualities as intelligence or creativity, or, conversely, lack of intelligence or lack of imagination, could be identified by genetic screening. But there are genes which can be identified; for excessive height, for example, or dwarfism; and numbers of more or less undesirable genes are being discovered all the time. The question then becomes, when is a genetic defect sufficiently serious to justify aborting the fetus that carries a faulty gene? There is already controversy over the chromosomal abnormality that gives rise to Down's syndrome. There are those who point to successful and happy Down's syndrome children and regard it as little short of murder to refuse to allow children like this to be born. They seldom take account of the fact that it is impossible to predict from prenatal diagnosis how seriously the individual baby will be affected, if born; nor do they recognise that Down's syndrome people are increasingly living longer and longer. Most Down's syndrome children used to die in their twenties of illnesses now curable by antibiotics or other treatment. Nowadays they may live to middle age or longer, and a happy child may develop into an impossibly aggressive grown-up who has to live in hospital.

It is easy to imagine the way that new genetic knowledge may increase the demand for screening and abortion, or selective implantation of embryos, to take account of the presence of genes responsible for a tendency towards Alzheimer's, schizophrenia, homosexuality, obesity, alcoholism or violence. Is this likely to become a situation where parliament will have to legislate, in order to block the way down a slippery slope? How, in that case, are they to decide what counts as a 'serious' condition, such as to merit the prevention of the birth of a child who would suffer from it? Are all parents to be treated alike in the application for genetic screening or are their particular circumstances and their ability to look after a more or less defective child to be taken into account? Are such decisions to be taken by individual members of the medical profession or must the conditions for abortion already laid down by the 1990 Act be made more specific, and the conditions for which pregnant women may be screened specified? It is inconceivable that these will not become questions with political implications. They are already questions of public policy about which it may be held that legislation is required. And it seems, sadly, unlikely that the tradition of the 'free' vote on such issues will survive for ever. Not just politics but party politics may become involved.

One reason why this may happen is that, with the new Bill of Rights, it is possible to imagine that there may be, one day, a legalised 'right to life'. The existence of such a right would affect not only debates about abortion but also about the treatment of children who have already been born. The case of Child B, some years ago, treated in the press as if she had a right to life, may become more common, and will involve ethical debates about the allocation of scarce resources.

Ableism

There is a growing belief, especially among groups of disabled people and also among post-modernist thinkers, particularly feminists, that it is a fundamentally unjust form of discrimination to select for birth only the healthy and non-disabled, whether by abortion of the defective or the implantation of only unaffected embryos (in the case of IVF). The general post-modern theory is that there is no one point of view, on any matter whatever, that is to be absolutely preferred to another. However, because some people are more powerful than others, they manage to impose their views on the weaker, and bring about that these are the views which dictate policy and command action.

The disabled are constantly put down, their point of view disallowed, because they are comparatively weak. The disabled therefore object that they, as a group with a particular point of view and particular common interests, are not only being disregarded (or 'marginalised') but that they are actually the victims of a policy which would eliminate them altogether.

In rather the same spirit, there is a specifically feminist objection to screening and subsequent abortion, or selective implantation, insofar as the medical profession is, if not exclusively male, nevertheless held to be dominated by a masculine ethos (women who practise gynaecology seem not to count as women). Women are portrayed by these feminists as the victims of medicine, forced, for example, to undergo infertility treatment, including in vitro fertilisation,
which endangers them and to which they are made to submit even if it is to remedy male infertility. More generally, they are the victims of a kind of eugenics which values the birth of a child, but only if that child is healthy. Thus women are forced to undergo screening and abortion of imperfect fetuses, or selective implantation in accordance with what a male-dominated society has arbitrarily decided are criteria of ‘healthy’ and ‘diseased’ (I am thinking here especially of the discussion in a book by the feminist Deborah Lynn Steinberg, entitled *Bodies in Glass*).

What is common to the disabled and the feminist groups is that both are inclined to place inverted commas round words such as ‘disabled’ or ‘handicapped’, thus implying that such categorisations are artificial social constructions denoting nothing essential in the person.

The prejudice in favour of the ‘perfect’ baby over the ‘imperfect’, the healthy over the diseased or disabled, is known, according to these theories, as ‘ableism’, and is comparable with racism, sexism or ageism. Now it has certainly come to be seen as part of the business of parliament to legislate, (with whatever degree of success) against unfair discrimination on grounds of sex or race, and there is already legislation in place to promote equal opportunities for the disabled. But none of this legislation denies the real existence, founded on real characteristics, of the different groups it aims to protect. People of different races exist in this country as surely as people of different sexes and different ages. None of these differences is held by anyone to be a mere artificial construction of dispensable and old-fashioned social institutions. But, in the case of the disabled, we are to understand from pressure groups that it is society itself which has created the category ‘disability’. It is society itself (or those powerful within it) which has disabled those so categorised.

The disingenuous (but also dangerous) aspect of these doctrines with regard to disability is that they emanate from and concentrate on people who have grown to adulthood, and who, though their disabilities are often serious, can nevertheless lead reasonably active and fruitful lives, provided that their needs are taken into account. These needs must be taken into account in, for example, the construction of houses, access to libraries and public transport, and in the development of new technologies. It is right that politicians, local and central, should be constantly reminded of the vast increase in freedom and in the fairness with which these people can compete for jobs that occurs if they are ‘enabled’ in all these various ways. But it would be disastrous to suppose that these are the only disabled people, or that they have very much in common with many of those babies who would be born if abortion of severely malformed or genetically damaged fetuses were not allowed, or if embryos were not selected for implantation where there is a risk of such damage. Such monogenic disorders as Lesch-Nyhan disease are not disabilities fit to be mentioned inside inverted commas. They are not social constructs. They cause immense suffering both to the babies born with them and to their families. Babies born with them do not live long enough to join a disabled lobby, even if they were capable of joining. Nor, as is sometimes alleged, does the natural preference of any couple for having a healthy baby rather than one with an inherited disease entail that those parents have no regard for people who have been born with or have acquired disabilities.

It is important that we (and I include politicians) should beware the rhetoric of ableism. Doctors who are confronted with babies suffering from real diseases cannot be accused of prejudice if they count these diseases as terrible disabilities. If it were possible, as one day it may be, to change the chemically faulty gene of a Lesch-Nyhan baby, either as an embryo, a fetus *in utero* or after he has been born, then doctors would make every effort to do so, just as they now make every effort to remedy a hare-lip, or operate on a baby born with annular pancreas. But until gene therapy is available, few would dispute that selective implantation of a healthy embryo or abortion after screening is the best option.

Putting to one side the absurd political correctness of ableism, there does seem to me to remain a real political problem about what counts as a disease, a problem which indeed already faces us in the interpretation of Clause 37(1) (d) of the 1990 Embryology Act, permitting abortion where the fetus is severely affected by disease or disability. Were genetic manipulation or gene therapy to become a reality, the problem would simply be relocated and another political decision would have to be made. Ought such treatment to be confined to somatic cells only, or in the case of some diseases should germ cells be treated? I believe that perhaps before so very long this is a question that parliament will have to address. If they do, they will be in need of the most knowledgeable and impartial advice that they have ever had to ask for. This would be a political decision which might, in the long run, affect the future of the whole human species.

There are other examples of the increasing politicisation of medical ethics, for instance euthanasia, or, most urgently, the question of the distribution of medical resources, but I hope my example has been enough to show how swiftly and inexorably medical ethics has become interwoven with public policy issues. There is a need to understand what is now possible and to be ready to make policy decisions in the light of that understanding, cautiously, but not too cautiously, looking ahead. It is a lot to ask, both of politicians and the public at large. Lay people are becoming dependent on medicine and science not only for the benefits on which we have always relied, but in a crucial new way: we need doctors honestly and dispassionately to educate us.

References:
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