Ethical issues in prenatal diagnosis

The techniques of early prenatal diagnosis, recently expanded and refined, were well documented late last year in the British Medical Bulletin. Current methods include screening programmes of at risk groups by estimating maternal serum α-fetoprotein concentrations, ultrasonound (including real time scanning), amniocentesis, and fetoscopy with or without fetal tissue and blood sampling. The new technique of chorionic-biops is of particular importance since this may be carried out in the first trimester, thus opening the way for early diagnosis and much earlier termination of pregnancy than is possible with other methods.

Such advances have obvious beneficial results. They improve the quality and quantity of information available to both doctors and parents; they alleviate anxiety in “at risk” pregnancies; and they make possible an increasingly accurate policy of selective abortion for congenital abnormalities, avoiding unnecessary terminations. Not everyone will greet such developments with unqualified acclaim. We may identify four interrelated issues of ethical controversy: the moral justification of selective abortion; the rights of parents against the rights of society in regard to decisions about the continuation or termination of a pregnancy; problems of consent and duress in relation to prenatal screening programmes; and questions of risk and benefit inherent in the development of new techniques.

The Abortion Act of 1967 legalised termination of pregnancy on the basis of predicted abnormalities provided that such abnormalities would be a serious handicap to the child if born. No definition of “serious” was offered, but the Act mentioned both mental and physical abnormalities, and in its other clauses it also allowed termination on the basis of risk to the mental health of the pregnant woman or to other children in her family. Thus the legislation appears to support
a liberal policy of abortion of abnormal fetuses, especially if the pregnant woman feels unable to cope with the upbringing of a handicapped child. The tests now available detect not only severe congenital defects of the neural tube (anecephaly and spina bifida cystica) but also metabolic and haemoglobin disorders and a range of chromosome aberrations including Down’s syndrome. Some writers see this enhanced information as a clear moral gain, allowing the avoidance of suffering, the weeding out of conditions which naturally selection would in any case discard, the earlier termination of pregnancies where the outcome for the fetus is inevitably fatal, and the continuation of those clearly established as normal. Others, however, fear the reappearance of a eugenic philosophy which regards all less than perfect human beings as inferior and promotes what would be better described as “ante-natal euthanasia.”

This difference in viewpoint on selective abortion seems as unlikely of simple resolution as that of the ethics of abortion generally. In the British legislation we have essentially a compromise which must bridge the gulf between two deeply opposed viewpoints. It will become increasingly important to hold on to this compromise if, with the increase in the use of prenatal diagnosis (especially the more acceptable first trimester testing), more and more prospective parents are in a position to consider termination on the basis of information now available to them.

The information offered to parents may include the determination of the sex of the future child. But should parents have the right to request termination solely on the ground that the baby would be of the “wrong” sex? With current legislation the sex of the fetus could be a criterion only in the case of certain sex related disorders. The parental right to decide the fate of the fetus is by no means absolute, and preferences for one sex or another could not be grounds for abortion.

What, then, of the opposite case where a mother is not willing to agree to termination even though tests have shown the fetus to be severely handicapped or perhaps the carrier of a deleterious gene? Should she be required by law to have an abortion in order to save the fetus from handicap or to relieve society of an economic burden? This again would clearly go well beyond the boundaries of the existing legislation, which deals only with requests for termination and is in no sense restrictive of the woman’s freedom to remain pregnant. A move in this direction would undoubtedly be the beginning of the eugenic social programme feared by the opponents of selective abortion.

The character of the compromise on abortion requires renewed emphasis when mass screening for defects is proposed. It may be tempting to propose that, to be fully effective, such programmes should be compulsory for groups clearly identified as being at risk—or that even if the test is not compulsory a requirement of undergoing the test would be that a termination will be carried out if the result is positive. But, as Powell and Fletcher point out, there can be no moral obligation, far less a legal obligation, to undergo prenatal diagnosis when there is a lack of moral consensus on the justifiability of abortion. Screening programmes must not contain any element of duress, however subtle and indirect. Their function is offering the best possible information to those who require it. If this information does not lead to a decision for abortion, it has still fulfilled a purpose in preparing the pregnant woman to consider the alternative options in good time. A failure to include such moral safeguards in screening programmes might lead to the stigmatisation of parents who produce disabled offspring—and possibly even an increasing refusal to provide facilities for the handicapped. In light of this, perhaps the term “screening,” with its implication of the discarding of faulty products, is itself unfortunate. The more neutral term “mass diagnostic programme” might be preferable.

Finally, the familiar problem of risk versus benefit arises in prenatal diagnosis. An earlier prenatal test such as chorion biopsy is obviously desirable to avoid the risk and trauma of later termination, but, though risks to the mother appear negligible, the risk to the fetus cannot be accurately measured. Should the more established techniques, where the risk has been accurately measured, be preferred, or should research continue to establish the safety of the new technique? And how much information should be given to mothers who become research subjects for the less well tried, but possibly preferable, new technique? These questions are not, of course, specific to prenatal diagnosis, but arise in all clinical research. The complication in prenatal diagnosis is that not one, but two individuals are affected. It has been suggested that a handicapped person might be entitled to sue his or her parents or their medical advisers for “wrongful life.” No court has upheld such a claim, nor does it seem likely that such a legal obligation to terminate another’s life could be established. But the moral (and possibly the legal) claims of those whose survival or postnatal development might be hazarded by experimental techniques are certainly stronger. For this reason a heavy responsibility rests on both parents and researchers, and it is surely essential that parents are given the fullest possible information when new techniques are being tested.

Progress in perinatal medicine cannot come about without some element of risk, but it is morally imperative that hazards to fetal life and health should be kept to a minimum. The primary purpose of prenatal diagnosis is the continuation of normal and wanted pregnancies—in which the welfare of both mother and fetus is the prime consideration. The emphasis on the elimination of handicap should always remain only a modulation of this dominant theme.

A V Campbell
Senior Lecturer, Department of Christian Ethics and Practical Theology, University of Edinburgh, Edinburgh EH1 2LX