the right to live

In order to free itself from a burden, does society have a right to say which lives are not worth living, or to judge the utility of any individual's existence?

BY JEAN JONCHÈRES

Over the last three decades medical progress, particularly in the field of molecular biology, has been so rapid that its potential practical applications have aroused some anxiety for the future of the human race. It is interesting therefore that advances in medicine have been paralleled by significant developments in the field of professional ethics.

First, a brief historical note. The 1948 Universal Declaration of Human Rights had its counterpart, in the medical field, in the Declaration of Geneva drawn up in 1948 by the World Medical Association (WMA). This was followed in 1949 by the International Code of Medical Ethics based on strict Hippocratic principles. Other declarations were published by the WMA in 1957, 1964, 1968, 1970, 1973 and 1974. To these may also be added various national codes of ethics and policy statements issued by the International Committee of the Red Cross.

Most of these codes and declarations are almost exclusively concerned with doctor-patient relationships, although today we also need a set of ethical principles to govern the links between medicine and society at large.

With the constant progress in science and new discoveries in biology, it has been generally recognized that studies should be encouraged, at the national and international level, into the ethical standards required to ensure that any medico-scientific research which involves human subjects safeguards their well-being and rights.

Although the basic laws of heredity were discovered by Gregor Mendel more than a century ago, scientific knowledge was until fairly recently insufficient to determine the causes of the all too common cases of congenital abnormalities in newborn infants.

The principal scientific advances that led to the elucidation of this problem were the discovery by O.T. Avery, C.M. MacLeod and M. McCarty that DNA (deoxyribonucleic acid) regulates heredity (1944-1946); the clarification of its mode of action by James D. Watson and Francis Crick (1953-1954); the determination by J. Hin Tjio and Albert Levan that the normal human has 46 chromosomes; and finally the identification for the first time (by Jérôme Lejeune, Marthe Gauthier and Raymond Turpin) of a human disease attributable to a chromosomal aberration. A further significant step was the description by François Jacob and Jacques Monod of the genetic regulation of protein synthesis.

Thanks to these discoveries, it proved possible not only to draw up a genetic chart of man but also to establish a list of congenital diseases. It is recognized today that between three and four per cent of all individuals are born with genetic anomalies. One-third of these are attributable to gene mutations, whose frequency is 1 per 1,000 individuals (per generation and per gene); the diseases in this group include haemophilia, albinism and various metabolic diseases (alkaptonuria, phenylketonuria, galactosemia, etc.). Another third are due to chromosomal aberrations—one out of every hundred persons is born carrying an anomaly of this type. Trisomy 21 (Down's syndrome, formerly called mongolism) is the most frequent example. The rest are induced by untoward events during the intrauterine life of the fetus, e.g., X-rays or other forms of radiation, rubella (German measles) or certain other viruses, and chemical substances.

The vast majority of the "errors" caused by chromosomal rearrangements or by gene mutations are of a non-beneficial character for the individual affected.

It is now possible to withdraw a specimen of amniotic fluid by uterine puncture, after having located the placenta, during the fourth month of pregnancy. A biochemical analysis is then performed on the amniotic fluid and on the cells after culturing and may show up any genetic anomaly. However, even where all appropriate precautions are taken, this technique is not without risk, both to the mother and to the fetus.

What then should our attitude be? While the matter is delicate enough where the results indicate a normal fetus, there are far more serious problems to be faced if it is ascertained that the unborn child will be defective at birth. Should one adopt the standpoint...
of the well-known French ecclesiastic Father Michel Riquet, who has stated that "it is certainly not the duty of the family and of the physician to force the hand of nature in order to preserve a monster that nature has predestined for early death"? I also recall that a few years ago I read a remark by an American gynaecologist who, on examining a newborn child suffering from serious malformations, asked himself whether he should not "allow the infant to die". Twenty years later, the child had developed into a fine young woman and a gifted musician... Hesitation and anguish may often be justified in such situations.

The proposal that the date of legal birth should be set two days after actual birth, in order to decide whether or not the newborn infant should be allowed to survive, is in my view unacceptable. Any approach along these lines would open the way to abuses and to legalized murder. Surely it would be more worthy and humane to create a network of specialized institutions to care for handicapped children. Parents would thereby be relieved of part of their suffering and would find some solace in the solidarity shown by society. The economic burden, often claimed to be an obstacle to this approach, would be no heavier than that entailed by the institution of systematic and compulsory prenatal screening.

This brings me to the question of biological check-ups on persons intending to marry. Should marriage be forbidden if one partner's genetic constitution is found to be incompatible with that of the other? In my opinion, no authoritarian decision should be taken in such cases. It is the doctor's duty to inform the couple of the risks they run, but it is up to the couple, and no one else, to assume their responsibilities.

What, however, should our attitude be if examinations in the course of pregnancy reveal the existence of genetic defects? In this case too, it seems to me, the woman or the couple, after having been provided with as precise information as possible, should be entirely free to make the decision.

My reasons for adopting these attitudes are the following:

- A pregnancy termination in the fifth month is not an easy procedure, nor is it without risk (the withdrawal of amniotic fluid can be effected only from the fourth month onwards).
- The proportion of abnormal fetuses is relatively low as compared with the number of births.
- The proportion of such fetuses that reach full term is also low (30 per cent of spontaneous abortions are attributable to chromosomal anomalies).
- There are therapeutic possibilities (which will certainly improve in the future) for treating genetic diseases in an increasingly effective manner.
- It is difficult to try to make a selection among the diseases detected and to classify them according to their seriousness. Can one make a distinction
between children affected by Down's syndrome and those manifesting Turner's syndrome (45,Y) or Klinefelter's syndrome (47,XXY), neither of which prevents certain affected children from leading an almost normal life? And in any such hypothetical classification, where do we place individuals with XYY-trisomy (47,XYY), who are considered to be potential delinquents?

Because of the impossibility of replying to questions of this sort, I feel it is unjustified to recommend the promulgation of laws determining how the doctor and the parties concerned should act. Every case has to be handled individually. The doctor has to act according to his or her conscience, and independently of his or her own political, philosophical or religious view. It is the doctor who must inform the woman or, where appropriate, the couple, and she or they must take the decision.

The determination of the genotype of the fetus thus makes it possible to determine in utero whether an anomaly or malformation is present. This is certainly a remarkable and in certain respects beneficial discovery and opens the way to new advances, particularly in the prevention and treatment of many diseases. At the same time, it has a major disadvantage in that the temptation may arise to abuse the technique, for example by destroying a human organism found to be defective. This, however, is by no means the most serious problem.

Quite apart from the hazards entailed by the technique (and the occasional errors in its application), the fact that it is relatively difficult (with few laboratories having the necessary facilities), and the fact that it involves expensive analyses, there is a far more disturbing threat. Under the pretext of improving the human race by eliminating individuals affected by hereditary defects or diseases or by altering behaviour and personality, is there not a risk that we will expose ourselves to a new form of slavery? What standards will serve as a basis for selection? By whom will the criteria be chosen? To put it succinctly, what is at stake is no more and no less than appraising and determining a set of "ideal criteria" for humanity with a view to obtaining a perfect society. Heredity—hitherto subject to the undoubtedly haphazard laws of destiny and chance—would in the future depend on the human will, or even the will of society. As far as I am concerned, I reject any such solution and the awesome risks it entails. At the extreme, one can envisage the elimination of a social group because it displeases the government.

Once the various processes of heredity and their mechanisms were known, it was obviously tempting to move one stage further. On the one hand, efforts have been made to correct anomalies, while on the other hand the introduction of deliberate and desired transformations has been attempted.

Without going into detail, we may perhaps recall that fertilization results from the fusion of two cells, a female gamete (the ovule) and a male gamete (the spermatozoon). These jointly create the first cell of the new organism, which thus combines both the paternal and maternal genetic heritages.

The procedures described as gene insertion or gene suppression are today covered by the popular epithet "genetic engineering". The metaphor has been stretched even further; it has been said that "we can envisage treating the hereditary material just as one repairs a motor... by replacing a defective part with a new one, or even by adding a part specially designed to improve the performance of the engine".

These prospects are the consequence of experiments conducted on animals, which demonstrate the possibility of transferring genetic material from one cell to another. It is in fact possible to incorporate in a given cell a particular chromosome originating from another species (hybridization) and thereby make good an enzyme deficiency. As a result of ever-continuing research advances, it has been proved that DNA can be transferred in vitro by a bacterial virus to a human cell, undergo replication in conjuction with the latter, be transcribed in messenger RNA, and ensure the synthesis of an enzyme originally lacking in the culture. (For the views of WHO’s Advisory Committee on Medical Research on this point, see page 13.)

On the other hand genetic studies have resulted in the discovery of a means of treating galactosemia. This disease used to lead inevitably to severe mental retardation in the affected infant unless early treatment, in the form of a galactose-free diet, was administered. Today, it can be treated with almost complete success. The same is true for phenylketonuria, a hereditary metabolic disorder often accompanied by mental deficiency.

In view of the fact that 1,500 diseases are now known to be of genetic origin, the discovery I have mentioned is clearly of great medical interest. And yet there is another, negative, side to the picture. Gene therapy is irreversible and raises serious moral problems. The extensive application of genetic engineering is still a very long way off but we are certainly justified in posing the question as to whether the temptation may not one day occur to introduce into the egg-cell a gene or group of genes intended to create a human being who is endowed with superior intellectual or physical traits, of a given size, having blonde or...
brown hair, or of a particular sex—the implication in the last case being the "suppression" of infants of the opposite sex. We would then have reached the era of Aldous Huxley's "Brave New World" and the "test-tube baby".

Sperm banks are already being set up; soon the sperm will be labelled and catalogued and its fertilizing capacity maintained for years by keeping it in a frozen state. To go even further, an entire human being could be kept in a state of "extended existence" by the same procedure.

Artificial insemination provides a solution to the sterility that prevents certain women or couples from having children. This is the positive side. But there are also important moral, even legal, problems to be faced (paternity, rights of inheritance, etc.). While artificial insemination need not be rejected, it must be applied with prudence and discernment and those concerned must be fully and accurately informed in advance.

There should be no significant ethical problems in the case of the implantation of a fertilized ovule, where the ovule originated from the subject herself. On the other hand, the same problems as for artificial insemination will arise where the ovule is derived from an alien subject.

In the final analysis, the objective of amniocentesis (withdrawal of amniotic fluid) and the use of genetic manipulation is to acquire a better knowledge of vital phenomena and to make it possible to develop methods for the prevention or treatment of certain hereditary diseases. And yet the risks are great, both at the level of the individual and of the community.

Certain persons or couples may use these techniques to seek greater individual satisfaction, better adapted to present-day society, but in defiance of moral and ethical principles. Certain nations may seek to exploit them for prestige, power and, most important, control. Is it not conceivable that governments may be tempted to apply genetic techniques to resolve problems posed by the "population explosion", to satisfy manpower needs for a particular category of workers, or to obtain a desired proportion of boys to girls?

Such hypothetical situations would have grave consequences for the medical profession by the harm they would cause to traditional professional ethics. The liberalization of abortion is already giving rise to reflection and is posing problems of conscience to many doctors. Besides his or her obligations to treat and comfort the sick, will the doctor be required to "suppress" his patients when effective means of treatment are lacking (as in the case of incurable diseases)? This somewhat apocalyptic hypothesis brings me to another point.

The primary duty of the doctor is to comfort and treat every person seeking his care, irrespective of the condition from which the patient suffers. If requested, the doctor must tell the
patient the truth about his or her condition, though with discernment and prudence. Finally, it is the doctor’s obligation to make the moment of death as comfortable as possible.

Many consider that the adjective “incurable” ought never to be used in taking a decision as to treatment: the number of persons considered as hopeless cases by their doctors and who are today in good health is impressive. Furthermore, a disease that is incurable today may become partly or fully curable tomorrow, thanks to the rapid development of new methods of prevention or the discovery of new means of treatment. There is no shortage of examples: insulin has provided a cure for diabetic coma, the surgeon’s lancet for the “blue baby” or mitral stenosis, and streptomycin for tubercular meningitis.

It is also clear that the ethical problems will differ depending on whether the patient is young or old, the nature or stage of development of the disease, the degree to which normal life is impeded, and whether or not physical or moral suffering is present.

A proposal advanced at the XXII International Symposium on Clinical Psychology (Lyon, 1970) to the effect that persons suffering from “complete and irreversible dementias or severe alienation states” should be purely and simply suppressed must be rejected.

In order to free itself from a burden, does society have the right to say that such lives are not worth living, or to judge the utility of the existence of thousands of persons? On what bases? Within what limits? The doctor cannot humanly accept this task.

The problem is to know whether it is legitimate and humane to voluntarily shorten a painful and hopeless existence; thereafter, the legal framework for the application of euthanasia has to be determined.

The proposal put forward by Francis Crick, the Nobel Prize-winning molecular biologist, to the effect that medical care should be withheld from elderly persons above the age of 80 essentially boils down to an indiscriminate death sentence that is not even worthy of discussion by doctors.

A preferable approach, in my view, is to try to define the moral and ethical indications for resuscitation. With certain minor shades of difference, these will be valid for the elderly as well as for young or middle-aged persons, whether they are accident victims or are suffering from a disease or progressive degeneration.

One might envisage two cases:

1. The person has been injured in an accident or been suddenly affected by a serious malaise, possibly involving a loss of consciousness, whereas he or she had previously been physically and mentally normal. The doctor must administer active treatment and pursue it so long as the monitoring systems (especially electrocardiography and electroencephalography) continue to show no cessation of circulation and cerebral activity.

2. A sudden or relatively sudden malaise has occurred after a period of several weeks (or even several months) of progressive deterioration, both intellectual and physical (the patient may be bedridden), or alternatively constitutes the final stage of a metastatic cancer. In such cases, tests of biological functions will after a few days at most reveal that essential organs have undergone profound deterioration, and it is both useless and inhuman to prolong the anguish of the family and “torture” the moribund person any longer.

Euthanasia

While one can accept, from both the moral and humane standpoint, the passive euthanasia reflected by the above cases and refrain from adopting what may be described as “therapeutic and technical relentlessness”, one cannot refrain from being very cautious indeed with regard to proposals for active euthanasia. At the very most, it is legitimate to alleviate as much as possible the sufferings and agonies of a very ill but lucid patient, who explicitly requests that he be helped to end his suffering. On the other hand, it is impossible to comply with any similar request emanating solely from the relatives of the patient.

“Your body is your own”, it has been said, and in consequence “only you have the right to determine what is to happen to it”. Some have invoked “the right to die”, a right that may be claimed by each individual on account of his or her liberty to decide. The role of the doctor confronted with a wish expressed in such terms is to inform, if possible to convince, but in the final analysis to respect the freedom of choice of the individual. It is incidentally rare for a potential suicide victim to clearly formulate his intentions in advance.

In certain countries, proposals have been advanced to deal with such problems: the drawing up of a restrictive list of cases for euthanasia; the establishment of special health councils to which doctors could submit difficult cases (proposed in the State of Washington, USA, in 1970); and the establishment of a board composed of several doctors, which would have the task of determining whether or not to apply euthanasia procedures. A symposium held in Paris in September 1974 favouring the idea of creating a “worldwide movement for responsibility in science”.

All these proposals would be valid not merely for euthanasia but also in other fields—molecular biology, genetic engineering, so-called incurable diseases, and the problem of the aged—on condition that the guiding principles were laid down by a “Supreme International Council on Ethics under the auspices of the World Health Organization and the Council for International Organizations of Medical Sciences”. This Council would be made up of scientists, practitioners, jurists and sociologists and would have to remain under professional control. One of the fundamental rights of every human being, i.e. “the enjoyment of the highest attainable standard of health” (to quote the WHO Constitution), could thereby be guaranteed.

It is always a delicate matter to legislate on matters of conscience and human behaviour. Moreover, the rigidity inherent in laws is scarcely compatible with the constantly progressing evolution of medical and biological knowledge.

Instead of being satisfied with the enactment of laws that are necessarily rigid and difficult to apply in individual cases, the authorities ought to become aware of the urgent need to provide increased material and moral aid to families with severely handicapped children, to all adolescents and adults suffering from physical or mental defects, to all the elderly persons isolated and abandoned in old-age homes, and, finally, to all at the moment of death.

Much would be achieved by better planning and layout of hospitals and nursing homes; a little human warmth could be introduced, notably by doing away with the coldly impersonal atmosphere of large public wards.

This assistance to the unhappy and despairing would cast a ray of humanity over our all too technical and materialistic civilization.