

Human values in genetics and embryo experiments

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Mapping the human genome

Medical science and technology have made great strides in recent times. The ethical values amidst the various achievements have to be evaluated as science tend to progress in isolation. In a recent conference of the WHO, in Tokyo, in which I was also privileged to participate representing India, some important decisions were made. Most of the nations were represented and included leading medical scientists and researchers. A declaration on medical ethics which is now known as the 'Tokyo Declaration' has come out as a product of this conference.

Discussion of human genetics is dominated today by the efforts now under way on an international basis to map and sequence the human genome. Such attention is warranted by the scale of the undertaking and its expected contribution to knowledge about human biology and disease. At the same time the nature of the undertaking concerned as it is with the basic elements of life, and the potential for abuse of the new knowledge which the project will generate are giving rise to anxiety. The conference agrees that efforts to map the human genome present no inherent ethical problems but are eminently worthwhile, especially as the knowledge revealed will be universally applicable to benefit human health. In terms of ethics and human values, what must be assured are that the manner in which gene mapping efforts are implemented adheres to ethical standards of research and that the knowledge gained will be used appropriately, including in genetic screening and gene therapy.

Do technical advances dehumanise the patient?

Public concern about the growth of genetic knowledge stems in part from the misconception that while the knowledge reveals an essential aspect of humanness it also diminishes human beings by reducing them to mere base pairs of deoxyribonucleic acid (DNA). This misconception can be corrected by education of the public and open discussion, which should reassure the public that plans for the medical use of genetic findings and techniques will be made openly and responsibly.

Some types of genetic testing or treatment not yet in prospect could raise novel issues, for example, whether limits should be placed on DNA alternations in human germ cells because such changes would affect future generations, whose consent cannot be obtained and whose best interests would be difficult to calculate. The conference concluded however, that for the most part present genetic research and

services do not raise unique or even novel issues, although their connection to private matters such as reproduction and personal health and life prospects, and the rapidity of advances in genetic knowledge and technology accentuate the need for ethical sensitivity in policy making.

Disclosure without consent

It is primarily in regard to genetic testing that the human genome project gives rise to concern about ethics and human values. The identification, cloning, and sequencing of new genes without first needing to know their protein products greatly expand the possible scope for screening and diagnostic tests. The central objective of genetic screening and diagnosis should always be to safeguard the welfare of the person tested: test results must always be protected against disclosure without consent. Confidentiality must be ensured at all costs, and adequate counselling must be provided. Physicians and others who counsel should endeavour to ensure that all those concerned understand the difference between being the carrier of a defective gene and having the corresponding genetic disease. In autosomal recessive conditions, the health of carriers (heterozygotes) is usually not affected by their having a single copy of the disease gene; in dominant disorders, what is of concern is the manifestation of the disease, not the mere presence of the defective gene, especially when years may elapse between the results of a genetic test and the manifestation of the disease.

Clinical application

The genome project will produce knowledge of relevance to human gene therapy, which will very soon be clinically applicable to a few rare but very burdensome recessive disorders. Alternations in somatic cells, which will affect only the DNA of the treated individual, should be evaluated like other innovative therapies. Particular attention by independent ethical review committees is necessary, especially when gene therapy involves children, as it will for many of the disorders in question. Interventions should be limited to conditions that cause significant disability.

The modification of human germ cells for therapeutic or preventive purposes would be technically much more difficult than that of somatic cells and is not at present in prospect. Such therapy might, however, be the only means of treating certain conditions, so continued discussion of both its technical and its ethical aspects is therefore essential. Before germ-line therapy is undertaken, its safety must be very well established, for changes in germ cells would affect the descendants of patients.

Responsibility of researchers

Genetics researchers and therapists have a strong responsibility to ensure that the techniques they develop are used ethically. By insisting on truly voluntary programmes designed to benefit directly those involved. They can ensure that no precedents are set for eugenic programmes or other misuse of the techniques by the state or the private parties. One means of ensuring the setting and observance of ethical standards is continuous

multidisciplinary and trans-culture dialogue.

The need of developing countries should receive special attention to ensure that they receive their due share of the benefits that ensure from the human genome project. In particular, methods and techniques of testing and therapy that are affordable and easily accessible to the populations of such countries should be developed and disseminated whenever possible.

Reproductive health care for women: a saga of excess, exploitation and violation

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Introduction

The health care scenario for women, especially apropos reproductive health, is highly exploitative, with extensive human rights violations. Women are treated as expendable entities.

Documented malpractice and possible cures

Malpractice has been observed and documented in the following medical interventions relating to reproductive health.

I Unsafe methods of abortion vis-à-vis Medical Termination of Pregnancy (MTP) Act.

MTP Act provides the right to safe abortion to women to prevent their exploitation at the hands of unscrupulous abortionists. This professed purpose has failed. Presently unsafe (illegal) abortions far exceed safe abortions, the ratio being 20: 1.

As a result, unsafe abortions today constitute the single largest cause of pregnancy-related deaths. This is because the safety provisions of the MTP Act are not implemented by the health authorities. Whilst this may be just another example of the ubiquitous lack of monitoring by concerned authorities, a more sinister explanation could be a deliberate 'blind eye' to achieve population control through MTP.

The safety provisions in MTP Act require approval and monitoring of a MTP centre to ensure required surgical facilities and approval of the doctor's qualification, competence and training. Abortion after 12 weeks of pregnancy is allowed only after consultation with two doctors and abortion is prohibited after the 20th week of pregnancy.

Remedy: Ensuring facilities for safe abortion by strict implementation of the provisions of the MTP Act and by taking legal action against health authorities who fail to do so.

II Unsafe Contraceptives

Intra Uterine Device (IUD) is inserted without proper evaluation of the recipient woman for genital tract infection. This can cause ascending infection leading to pelvic inflammatory disease with painful menstrual periods, blockage of fallopian tubes, resulting in sterility or tubal pregnancy and even peritonitis leading to death.

Laparoscopic fallopian tube ligations are carried out improperly. This is due to compromise of mandatory surgical norms by using unsterile laparoscopes or by using unsafe procedures in place of those prescribed e.g. peritoneal insufflation with atmospheric air in place of carbon dioxide. At times, a cycle pump has been used for insufflation. As anticipated, the procedure fails and is attended by an increased rate of complications as the result of these unhygienic and unsafe practices. These lead to a high incidence of ectopic pregnancy and catastrophic illness with high mortality even where surgical facilities are available. The situation is worse in a rural setting. The estimated number of such deaths due to faulty tubectomies is 500 for the 5 million ligations presently done per year .

The use of contraceptive pills without prior tests to ensure normal liver function constitutes a much greater hazard in our population as there is a high prevalence of liver diseases such as viral hepatitis (3% of our population is in the carrier stage of hepatitis-B while hepatitis-E is endemic) and amoebic hepatitis is common in our country. Other factors such as compromised liver function due to malnutrition, toxic damage from anti-tubercular drugs, consumption of aflatoxin from ill preserved food grains, toxic pesticide residues in food and water, and alcohol consumption increase the likelihood of liver disease in our population.

Remedy: Peers in the profession practising ethical medicine,. especially those practicing obstetrics and gynaecology should invoke and insist upon exact adherence to medical ethics framed under the Medical Council of India (MCI) Act.