

## Ethical Concerns Related to Medical Genetics

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**ABSTRACT** A great biochemist Erwin Chargaff, who discovered the parity theory of the DNA bases, once made a critical remark on the newly developed discipline of bioethics: "A fashion is going around the world, the fashion of bioethics. All the powers have entered into a holy hypocritical alliance with this fashion". With this remark, a parody of the first two sentences of Karl Marx's Communist Manifesto, Chargaff intended to point out the weakness of bioethics. Despite his skeptical views of bioethics, there are experts who discuss activities of biotechnology and grant the approval to the result of its research, including the bioethicists from genetic engineering companies like Monsanto and Novartis. Present article is an attempt to look into some relevant issues of genetics and ethics that defy our solution, especially with reference to the third world societies.

### INTRODUCTION

Ever since Johann Gergor Mendel, the father of genetics, enunciated the laws of heredity, the science of genetics has passed through revolutionary changes, giving birth to biotechnology and bioinformatics. The pace of revolution has been so tremendous and the application so mind-boggling that it has necessitated the birth of yet another discipline named 'Genethics' (Suzuki and Knudson, 1991). The developments in science, technology and society have to move together if humanity has to survive. Bertrand Russell the famous British philosopher remarked, 'Civilization is control of Nature, and Culture is control of Civilization'. What are the problems of this new discipline and how some of these issues can be tackled to maintain our social order and human values need to be discussed threadbare and guidelines drawn to regulate activities in this field.

The problems raised in the media and press can be broadly classified under four categories, namely, those related with environment and life forms, with health and diseases, with the science and social values and finally knowledge itself (Rose, 1994). Such is the scale of impact of the new revolution that the problem is felt globally, not locally ("glocally") and the impact is universal, not cultural. Thus the state-science industry-market nexus (Rose and Rose, 1976) coming closer

and tighter day by day, affects society and individual rapidly, and the impact of globalization, liberalization and privatization exacerbates it further. Unless proper ethical measures are adopted, the change will engulf the entire society and man will vanish into a robotic creation handled and controlled by the elite to further their narrow ends. Fortunately, such concerns have been felt deeply and various fora have been formed for raising and enforcing these issues.

Evolutionary biology, combining behaviour and ecology, has given birth to the discipline designed as sociobiology (Wilson, 1978). This science has proven useful in ethology and social behaviour of animal species. An extension of this in man has been advocated by Edward O Wilson who has presented an animal basis for human society and even suggested biotheology. This reductionism has been debated by anthropologists and ethnographers.

The recombinant-DNA revolution (Berg et al., 1978; Watson and Tooze, 1981; Krimsky, 1982) resulting into bio-technology has opened a Pandora's box, in that, man has brought, Nature's evolution to the laboratory innovation, however, without a clear idea of environmental consequences. A new organism 'transgenic' can bring disasters if it interferes with the natural ecosystem and upsets the Natural balance. What are called as GMO, (Genetically Modified Organism), are but the result of this effort today, the terminator seed technology poses yet another threat.

The last to be added to this gamut is the human genome revolution and the cloning technology (Wilmut et al., 1997) The most remarkable thing about human genome is that it is the ultimate in reductionist method of science,

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man has been reduced to a chemical formula of DNA bases, a giant molecule whose key lies in the hands of scientists. This is not simple knowledge of composition of body, as many would think, but how can we construct a human cell and the human organism from the building blocks? The benefits that follow would be in pharmaceutical industry and multinationals will exploit this by patenting these sequences. The somatic cloning is another tool by which a human clone can be raised and thus a desired copy produced. Cloning is therapeutic when it is used to cure some disease and it is reproductive when it is to produce a young one, though it is fraught with dangers in human development (Jaenisch and Wilmut, 2001). Clone's right as individual or person will be jeopardized as he can be a property, not a creature. The crises posed above are thus concerned with the environment, science itself (reductionism vs holism), individual's health and finally the society whose concern has been raised by many scholars (Susanne, 2004). It is with the last two that we can now turn in the gamut of clinical genetics and medical ethics.

### MEDICAL GENETICS

The area of clinical genetics is already under active service and social consequence are being faced, hence the current ethical problems (Ruth and Sue, 1984). There are currently four thousand genetic disorders which are hereditary and hence transmitted from parents to the offspring. These are produced by disease carrying genes unlike normal genes, and cause disease which cannot be cured permanently. The challenge is open for gene therapy, at present, it is in infancy stage. Therefore, management of genetic disorders has three approaches-genetic counselling, genetic screening and gene therapy. The genetic counselling has two stages: prenatal (before birth) and postnatal (after birth). It is the prenatal one that is more important.

*Amniocentesis* the amniotic fluid from the womb is withdrawn through intravaginal or transabdominal route and the fluid is collected through a sterile catheter and taken into a test tube (Sutton, 1985). The cells are cultured and the karyotypes prepared, the abnormal karyotypes confirm the chromosomal disorders and the foetus is terminated by MTP. The law for amniocentesis exists but unfortunately, the normal female foetuses are also being aborted, resulting into dwindling female population. The alternative

technique called chorionic villus sampling (CVS) is safer, as it needs only four weeks of pregnancy period and abortion is less traumatic. The ethical issues are here two-fold the health of mother and the health of foetus which is more important. Anti-abortionists and foetal rights group have a consternation from feminists who give primacy to mothers. When does foetus acquire person-hood, a general consensus is the formation of primitive streak or development of nervous systems. Foetal medicine is still in infancy and therefore, ultrasonography, echolocation, echosounding and other techniques will better focus on the area.

The problem of genetic screening poses yet another problem. What if prospective partners can be diagnosed for carrier-status, the suppressed or recessive genes of parents get expressed in the child if the child inherits both the recessive gene (1 in 4). This is preventive method to check the birth of such children either by preventing marriage or if married, checking all the foetuses. Now this poses a castigation (King's Fund, 1987) upon the carriers who would be taken as some abnormal being and hence witchhunting can start. Complete confidentiality may not be possible and social problems can result.

With this is also related the problem of ethnic origin of some disease, like cystic fibrosis in Ashkenazi jews, the thalassemias among the Cypriots and Mediterraneans and, in India, amongst the Sindhis and Punjabis (Balgir, 2000). Such screening is to be made compulsory for risk groups and can lead to the notion of imperfect race and hence persecution by some zealots, in the name of cleaning the gene pool.

The third measure for correction of genetic diseases is gene therapy (Anderson, 1992). Here the problem of clinical trial with informed consent is important. Even death has resulted due to the gene therapy protocol and some consent is important and some animal models or primate trials have to be perfected before application among humans. Many types of cancer are awaiting gene therapy in absence of proper trial. Suspicions are thus raised when developed countries undertake the trials in underdeveloped countries, and the lure of petty money brings make-belief consent. The havoc can be imagined.

### Reproductive Technology (Austin, 1989)

The problem of ethics in health science can be nowhere as disastrous as in fertility research.

Here the problem is acute for the female, childhood and family relationships, and some of the technological break-throughs have brought unforeseen consequences.

- (i) IVF (*In vitro* fertilization) (Walters and Singer, 1984): The first test tube baby Leslie Brown, attempted by Edward Steptoe, has brought making of the babies a laboratory exercise. This has worst hit the surrogate mother, whose womb is rented for nurturing the foetus after which she has to bear the trauma of infant separation and motherhood.
- (ii) Genetic Vs social parentage (Snowden and Mitchel, 1981): The technique of Artificial Insemination by the Husband (AIH) gives child social and biological parentage both, but by an anonymous donor, it is not biological. Hence inheritance rights are at stake of the child. Surrogate mother, similarly, has no right. The social parents give family to the child, whither inheritance rights?
- (iii) Surrogacy of brain (Shanon, 1988) dead woman, imbeciles: This is abominable, the woman being used as vegetative sac to deliver a child and then cast away from the child, even animals are not allowed to do so.
- (iv) Multiple births (Singer and Wells, 1984): Usually in case of test-tube baby, more eggs are fertilized in the petridish and transferred to the uterus of the mother, who rears multiple offspring. What about the infant, if not accepted by the social couple.

#### Embryo research (Ciba Foundation, 1986)

Unlike foetus, an embryo is a mass of cells derived from a single fertilized egg capable of growing into a foetus and adult. The embryo lacks a personhood status, so to say, and is a life mass, if not life itself, which includes a cell. Embryos are undifferentiated and hence capable of giving rise to all types of cells. The stem cell of embryo, therefore, is cultured to produce tissues such as neurons, muscles, skin cells and blood and used for tissue therapy. Unlike adult tissues which have identity (HLA antigens) and get rejected in Xenotransplantation, the embryonic stem cell of the same individual can be an individual's own stem cell. One approach is taking nucleus out and putting it back into egg cytoplasm (whose nucleus has been ejected) and its development to an embryonic state (cloning strategy) and hence getting some cells for treatment. This is

therapeutic cloning, and hence its use for treatment of Alzheimer's disease, Parkinson's, disease and senile dementia (Hansasrd, 1990).

While embryonic culture is allowed (Warnock, 1985) spare-embryos can well be discarded which amounts to a type of homicide. Frozen embryos can be used but discarded embryos can be used to produce chimera or a somatic monster. Designing such somatic hybrids may lead to a baby derived from four different parents or man-mouse or similar hybrids. Where do we classify such creatures, transgenics and what will be their behaviour? Such type of research looks a plot straight from a science fiction at present, but the technology is available, only ethical sanction is not. A strange technique called 'headless cloning' is yet another innovation where tampering with a few genes can produce organs which can be used for transplantation.

When technology for manipulation of tissues and cells become common, the organ trades of poor people's bodies can become rampant and the commercialization of body will go full circle.

#### Trait Genomes for Sale

We are not far away when the complete knowledge of all the 30-40,000 genes, their protein products, the tissue and organ development, and regulation will lead to manufacturing human traits of beauty, intellect, sports activity, musculature and even personality traits viz. aggressiveness, homosexuality, criminality and selfishness (Stepan and Adams, 1990). The completion of personality requires a rearing approach but genomic underpinnings can be exploited to further ulterior causes. Nature's ingenuity in distribution of such traits along either side of the binomial curve can be useful for the good of the population through generations and hence a balance of genetic elite against genetic load; beauty in diversity. Can interference in this scheme bring about a totalitarian shift to utilitarianism and hence loss of genetic diversity to monolithic variants called monoculturing.

Behind these developments of genetics and biotechnology is not the genuine desire of scientists to know the secrets of life but the materialistic motives of market and state sponsored research to dominate the economy and beat the rate race. There is a complete lack of restraint to shape the development of the field; the basic scientists are not addressing Nature's

questions, or diverting research towards higher orders of life such as ecology, which allows for the webs of life and environment's protective power. A short sighted approach at synthesis of life materials is operating which, unlike the tampering of non-living material, can directly attack ecosystem (Non living material act by adding to mass; living forms act by changing the mass and hence are more powerful). A definition of life outside the environment is not possible; it can only be taken with respect to higher organization. Thus the path from DNA to cell is the same as from cell to organism and from organism to environment. With the organization called ELSI (Ethical, Social and Legal Implications) of Human Genome Project, Human Biodiversity Project, and sequencing the Human Genome, various ethics committees have come forward in addressing these questions. Rights of aborigines, minorities, women, homosexuals, poor and even foetuses have to be kept in mind. Church, local traditions, politicians, administrators, media personalities, teachers and scholars have to come together for formulating guidelines to monitor and guide the output of genetic research. It appears that the Baconian method of science in separating facts from values has played heavy with human genome research, if Nature can't be taken sacrosanct, at least human action has to be ethically bound. Unless this happens, science will unleash the proverbial Faenckstein monster, and, the Greek myths once again will raise the diabolical headed as Prometheus Unbound.

### **Social and ethical**

The social implications of biological theories which emanate from Darwinism do not come in the purview of genetics and ethics question. However, serious offshoot of early twentieth century biological research is the so-called sociobiology debate of Edward O. Wilson. This is not the result of genetic research but evolutionary biology's ill-begotten child. Unfortunately this debate is beset with lack of scientific evidence. This is steeped in maximization of fitness concept; hence the lack of any higher values in life forms. Richard Dawkins (Dawkins, 1976) over emphasis on selfish gene is taken as some form of a Darwinian dominance and explantation of even altruistic behaviour. Unfortunately rape, violence, gender discrimination and promiscuity are read into man's biological blue-print and justification of capitalism and

colonialism is allowed. There seems to be little justification for this theory, man's behaviour is still under study; human brain-mapping is to follow; and this will bring out the role of perception, language, culture and even inspiration from religious leaders to outgo the baser instincts. The use of theory as a tool to dominate is age long; hence this also needs to be applied with reservations, and so, to say, can meet with the same fate as did Freudian or Marxian doctrines in the last few decades (Wexler, 1990).

### **Genetic determinism**

The question has led to the final stage of genetic determinism which has come to dominate scientific meetings including the one from India (Discussion Meeting on Genetic Determinism, 2003). To quote Prof. V. Nanjundiah, the organiser of the meeting, "The implications of current advances in molecular biology, which tend to be grouped under the name of the recombinant DNA revolution, are staggering. For the first time they enable us (at least in principle), not just to talk about genes as material entities, but also to handle them in the way we handle other objects using the methods of physics, chemistry, engineering or medicine. There is a big difference, of course, in that the manipulation of genes affects not just the individual organism that carries the "new" genes, but also its descendants.

As in the beginning to be recognised, the ability to use recombinant DNA technology in a facile manner throws up issues that deserve consideration. Implicit assumptions that lie behind the promise and the often hyperbolic forecasts that are associated with genetic engineering require examination. It is vital that we debate the relevant issues, especially with reference to what is likely to happen in less developed countries where resources are few and claims for potential benefit are many ethical as well as scientific questions are involved, precisely because of the possible economic consequences of large scale genetic manipulation of plants and animals, the way in which the world's national economies interact with one another means that these unanipulations have long-range implications for international relations".

### **CONCLUSIONS**

It is rather frightening to ignore the grave consequences of pernicious philosophy and

draconian measures to be attempted by some vested interests sponsored for materialistic returns from the genetic engineering. The ethical basis of humanity has been long recognized in almost all societies since pre-Christian days, especially among the oriental societies. The need is to strengthen bioethics programmes in academic institutions and increase awareness among the people. It is with this motive that an Asian Bioethics programme was initiated by Eubios Ethics Institute, Japan and New Zealand. Its secretary Mr. Daronyl Macer (2003) in the conclusion of the Fourth Asian Bioethics Conference, held on 22-25 November 2002 in Seoul National University, Seoul, South Korea, remarked. 'Let me conclude with some points on the recognition of diversity and the depth of Asian Bioethics. Our scientific evidence to date suggests bioethics is pre-human, the principles of autonomy, justice, beneficence and non-maleficence were important for the bioethics in human culture. They have been discussed for millennia in Asia. No longer please say that bioethics is a US invention, as they claim. Bioethics was here before we know it. It is a global realization of an invention that occurred before people were aware of it.'

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