

Committee 2  
Genetic Knowledge, Human Values  
and Human Responsibility

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ISLAMIC PERSPECTIVES ON GENETIC INFORMATION USE AND  
GENETIC TECHNOLOGY

by

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No doubt today an immense genetic knowledge is being accumulated. This sum of knowledge would not have been possible without the extensive genetic research which had been going on for sometime in many countries specially those of the developed world. Several ethical issues and controversies surrounded genetic knowledge and research. Consequently opinions towards it varied from complete banning to encouragement and support. In 1992 the European Community (EC) funded a study group to explore the ethical implications of Human Genome Analysis for clinical practice in Medical Genetics with special reference to genetic counselling. (1)

Genetic researches on human subjects are part of medical research in general and the ethical requirements and rules of medical researches should apply to them. They should be governed by previous international guidelines relevant to this problem such as the Nuremberg and Helsinki Declarations (1964 and 1975), the CIOMS (1982), the Inuyama Declaration (1990), and the Cairo declaration of (1991) for the Muslim Countries. (2)

### **Basic Ethical Issues of Genetic Knowledge and Research**

When discussing the ethical issues of genetic knowledge and research one cannot ignore principlism in medical ethics. Principlism is usually understood as the application of the four principles of biomedical ethics outlined by Beauchamp and Childress namely autonomy, beneficence, nonmaleficence and justice. (3) Principlism may also be understood that medical ethics should be approached by applying some set of principles, not necessarily those four. (4) Both views have been criticised. The first on the grounds that the four principles are not sufficiently grounded from a theoretical point of view. (5) Both approaches were criticised from the perspective of an alternative ethical approach called the ethics of care. (4)

The application of genetic knowledge and research should abide by the following principles:

a- It is in the interest of man.

- b- It causes no harm to the individual, fetus, mankind or society.
- c- Autonomy which involves autonomy of the competent persons and protection of those incapable of autonomy.
- d- Justice both distributive and corrective.
- e- Academic integrity.

Respect for the individual's freedom of choice should be observed. Coerced participation in genetic screening and research is inadmissible and a free informed consent should be obtained from research subjects after explaining the research and its implications to them. If genetic research involves the fetus, the free informed consents of both parents must be obtained in advance. (2)

Justice dictates that the beneficiary of scientific research results should be the society which took the responsibility of the research and subjected its members to research risks. (6) Population based genetic research conducted in the various countries should, therefore, be concerned with the health problems of each of them and be beneficial to them. They should not aim only at serving other countries without benefiting the countries where the research was conducted.

Moreover, distributive justice should be secured within the society when such researches are conducted. This means that the research should not be conducted on a particular class of the society, such as the poor, whereas its basic benefits would accrue to another class, such as that of the rich. Genetic therapeutic research resulting in a costly treatment which only the rich can afford, although the preliminary experiments were conducted on the poor classes of the society, represents a serious violation of this principle of distributive justice. Hence, when such researches are conducted, the research sample should be as representative as possible, covering all the classes of this particular community socially, economically, culturally and religiously. They should not be limited to one particular class of society. Also distributive justice should be observed when applying therapy resulting from genetic researches. Therapy should take no account of creed, sex, the size of classes (majority or minority) or political privileges. (2)

Corrective justice is concerned with compensation of the wrong act. It corrects an imbalance of rights and duties among society members. It restores the position that existed or should have existed before a wrong act was done. In population based genetic research group compensation involves issues of resource allocation and access to scarce benefits, and more particularly the difficult situation of possible compensation for other generations which may be affected by conducting such research.

Academic integrity and honesty are upheld not only in research design and implementation, but also in the presentation and publishing of research data. Within the academic world, there are occasional cases of fraud or falsification, or cases where expectations regarding the results of research are published prematurely or where scientific pronouncements are made on the basis of the researcher's own prejudices. There are also incidents where researchers not uncommonly dispute the privilege of a scientific discovery or the scientific value of other's research. Also research sometimes is carried in one place as developing countries while it is impossible to be carried in another place because of statutory provisions. The problem of double standards is under discussion in various international forums. (7)

#### **Islam Background :**

Islam is a faith which had over 1.225 billion adherents world wide in the year 1990, and with the present rate of population growth this figure is expected to increase to 2.5 billion in the year 2020. (8)

Islam is a comprehensive system that regulates the spiritual as well as civil aspects of individual and communal life. It aims at producing a unique personality of the individual, and values. The Teaching of Islam covers all the fields of human activity - spiritual and material, individual and social, educational and cultural, economic and political, national and international. (9)

Instructions which regulate everyday activity of life to be adhered to by good Muslims is called Sharia. There are two sources of Sharia in Islam : the primary

sources and the secondary sources.

*a. The primary sources of Sharia in a chronological order are :*

- 1) The Holy Quran : the very word of God.
- 2) The Sunna and Hadith which is the authentic traditions and sayings of the Prophet Mohamed (Peace be upon Him) as collected by specialists in Hadith.
- 3) Ijmaah which is the unanimous opinion of Islamic scholars of Aimmah.
- 4) Analogy (Kias) which is the intelligent reasoning by which to rule on events the Quran and Sunna did not mention by matching against similar or equivalent events ruled on.

A good Muslim resorts to secondary sources of Sharia in matters not dealt with in the primary sources.

*b. The secondary sources of Sharia are :*

- 1) Istihsan : which is the choice of one of several lawful options.
- 2) Views of Prophet's Companions.
- 3) Current local customs if lawful.
- 4) Public welfare.
- 5) Ruling of previous divine religions if not contradicting with the primary sources of Sharia.

*c. The Sharia classifies all human actions without exception into one of five categories.*

- 1) Obligatory as praying and fasting.
- 2) Recommended as marriage and family formation.
- 3) Permitted as breaking fasting during illness and travelling.
- 4) Disapproved but not forbidden as divorce.
- 5) Absolutely forbidden as killing and adultery.

Even if the action is forbidden, it may be undertaken if the alternative would cause harm.

The Sharia is not rigid or fixed except in few legislations as worship, rituals and codes of morality. Islamic Sharia accommodate different honest opinions as long as they don't conflict with the spirit of its primary sources and are directed to the benefit of humanity.

The development of the science of Fiqh (Jurisprudence) resulted in establishment of certain guiding principles to help to drive rulings. There are several principles upon which the science of Fiqh is based, such as : Harm should be removed, the choice of the lesser of two harms, and the public interest takes priority over enjoying benefits.

The goals of Sharia can be summarized in the preservation and protection of self (life, health, procreation, ...etc.), mind (prohibition of alcohol, freedom of thought, .... etc.), religion (freedom of faith, non compulsion in religion, rituals of worship, ....etc.), ownership (scantily of private ownership, legitimate commercial relationships, prohibition of stealing, fraud, and usury, .... etc.) and honor (purity, marriage and laws of family formation, chastity and prohibition of adultery, ... etc.) (10).

In Muslim Societies first and foremost account should be taken of the provisions and spirits of Islamic Sharia in formulating rules and guidelines, taking into account local and social conditions of the society where the research is conducted. In Islam, being a religion of mercy and compassion, one should not inflict any harm on human beings or animals in conducting, or applying the results of such research. (11)

### **Genetic Information & Genetic Technology Use :**

The use of genetic information had been rapidly expanding over the past few years. This would not have been possible without the vast development of genetic technology. Today genetic information applications include :

- 1- Research on surplus embryos in In-vitro Fertilization programs (I.V.F.)
- 2- Genetic research on fetal tissues and abortuses.
- 3- Prenatal genetic diagnosis.

- 4- Fetal selection.
- 5- Identification of newborn with metabolic disease.
- 6- Identification of harmful gene carriers.
- 7- The human genome project and gene therapy.

#### **Genetic Research on Human Pre-embryos :**

In IVF programs excess pre-embryos can be and are used for genetic research in some centers all over the world. This raises an important ethical question concerning the ethical implications of such researches.

Science tells us that the human embryo which is the little clumps of cells is the beginning of human life. It can be shown to be human by the nature of its genetic material, DNA, and the structure of its chromosomes. These components contain the information in chemical code for the development of the embryo into a human person. However, one must not forget that it is not only the human embryo that is genetically unique, but every sperm and ovum is also genetically unique. They have all arisen from meiosis, the cell division in the gonads. At that time, as the number of chromosomes is halved, the genetic material is exchanged between sister chromatids to produce a completely new arrangement. During the long process of maturation of the germ cells, the genetic material is further modified by imprinting, producing even more genetic uniqueness for each ovum and sperm. However, one must not forget that not every sperm cell and ovum or even an embryo develop into a human person. There is an enormous natural prenatal loss which is known to occur. Indeed if everything is favorable then a human being gradually emerges in only about 20% of embryos. It is, therefore, not surprising that some ethicists and scientists do not consider a human embryo as a human person and may, therefore, allow experiments on it which involves its killing. (12) However, these scientists admit the potentiality of human embryos to develop into a human person. This means that great respect must always be accorded with it. Experiments which may harm the embryo, while still allowing it subsequently to realize its potential and become a

person, should not be permitted. (12)

The classic Thomistic definition of the person is "an individual" substance of rational nature. The "individus" is the Latin translation of the Greek "atomos". This means that an individual means an " indivisible" entity. Science had shown that up to 14th day from fertilization the embryo can split into two or more without dying. Therefore, it does not satisfy the definition and hence is the term "pre-embryo" to indicate this period of development.

The existence of the higher brain is necessary for any form of human rationality. As science shows that the higher brain only develops several weeks after fertilization, the embryo, therefore, is not a person. This is far from the concept of Iglesias and Serra who consider the embryo as a person from fertilization. (13,14) Surveys of the bioethics literature on personhood showed the great difficulty of arriving at an agreed upon set of criteria for personhood. (15)

Fetal development has been viewed by Muslim theologians as occurring in three stages, each lasting 40 days, the sperm cell and ovum, the blood like clot and the lump of flesh (fetus). At the end of these stages, the fetus is ensouled. This concept is based on the verses in the Holy Quran and explanatory Hadith of the Prophet Mohamed (peace be upon Him). The Holy Quran says: "**Then We did create from a quintessence (of clay). Then We placed him as (a drop of) sperm in a place of rest, firmly fixed. Then We made the sperm into a clot of congealed blood; then of that clot We made a (foetus) lump; then We boned and clothed the bones with flesh; then We developed out of it another creature. So blessed be God, the Best to create**". (16)

The Prophet Mohamed later explained that each phase of this development lasts for forty days. (17)

From a Muslim perspective, excess pre-embryos in IVF program can be used for genetic research purposes provided the free informed consent is obtained from the couple.

It should be reiterated that the researches conducted on pre-embryos should be limited to therapeutic researches. The treated pre-embryos shall be transferred



only to the uterus of the wife who is the owner of the ova and only during validity of the marriage contract. This should be applicable to researches involving microsurgical techniques as sperm pronuclear extraction to correct polyspermy and genetic diagnosis of a portion of the embryo, one blastomere or its nucleus for a specific genetic defect. (18,19) As excess pre-embryos are the property of the couple, the free informed consent of the couple should be obtained before these pre-embryos are subjected to non therapeutic research. These pre-embryos are not to be transferred to the uterus of the wife or that of any other woman. (2,19,20,21,22)

Researches aiming at changing the inherited characteristics of pre-embryos including sex selection are forbidden as this constitutes a challenge to the will of God. (11) Researches of commercial nature or those not related to the health of mother or child are not allowed.

Respect for the origin and human character of the pre-embryos dictates the restrictions placed on the researches conducted on them. Research should be conducted with specific goals, on a very limited scale and under strict control. The researches should be conducted in research institutes of sound repute such as specialized research organizations. The researchers should have medical justification and should be a qualified skilled researcher.

The past few years had witnessed marked improvement in pre-embryo research as well as legislation of such researches in some countries. This has evoked the old ethical concerns about techniques and approaches which can alter our inner environment, introduce changes in our very genetic constitutions and structures and enable us to influence the kinds of people who are born. (23,24) The answer is not suppression of research in these areas but study committees and other groups to monitor developments and make statements when such need arises. (23)

**What ethical limits should be set in relation to research on pre-embryos ?**  
Should such research be conducted solely for the purpose of improving in vitro

fertilization or are other aims permissible? Study of teratogenicity of nicotine, growth of malignant cells or effect of certain medicaments are examples of these studies. How far is it permissible for the research to go as optimization of pre-embryo development, cloning, hybridization ?

#### **Genetic Research on Fetal Tissues and Abortuses :**

Is research performed on fetuses or fetal tissue obtained from abortions permissible. Examples of these are researches connected with transplanting fetal thymus tissue into humans and the transplantation of fetal tissues into patients suffering from Parkinsonian's disease. (7,24) From a Muslim perspective, such research is permitted, provided the free informed consent of the couple is obtained.(2) Maturation of human oocytes outside the body is another area of ethical concern. Its impact on the management of some infertile patients would be a break through in this field.

#### **Prenatal Genetic Diagnosis :**

Recent advances in prenatal genetic diagnosis have significantly increased the possibility of genetic selection. If a serious genetic disorder is detected during pregnancy, the woman may choose an abortion in order to prevent the birth of a severely handicapped child. A model of this prenatal screening is the detection of Down's syndrome, Trisomy 13 and 17 and anencephaly. Is the choice of abortion in this case an illicit act? In the western societies discrimination among persons is strongly condemned. If the embryo is a person then we have towards it obligations as strong as we have towards any other person, but if the embryo is not a person or we do not know whether or not it is, then our obligations towards it are much weaker and practically non-existing. Some authors believe that genetic selection ought to be prohibited because its diffusion is going to change in a fundamental and disruptive way the nature of parenthood. Others believe that genetic selection ought to be permitted because it allows parents to have healthier children. (25) Some authors would support that governments should provide

voluntary testing facilities, extensive dissemination of information concerning genetic diseases and genetic counselling services. (26) Confidentiality should be guaranteed to participants in these programs. Diagnostic aids should be provided for people in high risk categories for genetic diseases. Should the fetus be found genetically defective, the abortion decision should be left up to the individuals after proper counselling by the physician.

An ethical controversy over fetal anomalies and viability is being raised in reference to the role of newborn intensive nurseries who are sustaining the life in severely deformed babies for the purpose of organ donation. (27)

Islam has given a great importance to prevention of congenital malformation. Seeking to protect the well-being of children, it advised man to choose his wife with great care. The Prophet (peace be upon Him) said: "Select your spouse carefully in the interest of your offspring because lineage is a crucial issue". He also said: "Do not marry your close relatives because you will beget weak offsprings". Omar Ibn El-Khattab, one of the Prophet's Companions, noting that the Saib tribe intermarried too frequently, told them: "You have weakened your descendants. You should marry strangers". Islam has also determined the rights of the fetus, that the mother should not harm or expose the fetus to harm. (28).

From a Muslim perspective, if abortion is performed to protect the mother's life or health or because of a fetal anomaly incompatible with life, it is acceptable. (2).

### **Fetal Sex Selection :**

The prenatal genetic screening for sex selection or very early selection of the sex of the embryo in IVF programs poses the ethical question of the right of the mother to choose the sex of her baby. This opens a wide and conflicting debate around non-ethical discrimination against female fetuses in favor of males. Non-therapeutic fetal sex identification and selection and its implications on reproductive self determination and women's or couple's choices is likely to be a

topic of debate in international forums. Sex selection was practiced by the Arabs before Islam when female babies used to be buried after their birth and Islam forbidded such selection as this constitutes a challenge to the will of God. (2,11,28,29).

#### **Identification of Newborns with Metabolic Disease :**

Another model of genetic screening is the identifications of newborns with metabolic deficiencies such as phenyl-ketonuria so that these babies might receive early appropriate medical treatment.

Such model of genetic screening is certainly ethical and part of good medical practice which should be applicable whenever indicated or suspected by the treating physician. From a Muslim perspective, this is encouraged as it alleviates the suffering of human beings. (2,22)

#### **Identification of Harmful Gene Carriers :**

Another model of genetic screening is the identification of carriers of harmful genes before they get pregnant or have a family. Appropriate counselling of these carriers may help them tremendously in making an enlightened decision about their childbearing choices. Programs to detect Tay-Sachs disease, sickle cell anaemia, and cystic fibrosis as Huntington disease, are some examples of this situation. Disclosure of such information to the couple on their request is certainly ethical and may help them in taking an enlightened decision and prevent a later unhappiness and disappointment of childbirth outcome.

Correlation between genes and diseases and possible genetic basis of undesirable xyy chromosome linked to violent and criminal behavior represents an area of ethical controversy.

The international project, Human Genome Project, is underway to identify and locate all the 50,000 genes humans possess. The Human Genome Project had led to the discovery of some genetically transmitted disorders. This has and will

increase our understanding of the relationship between a person's genetic traits and his/her future health risks. New genetic tests are expected to expand the scope not only for genetic counselling, but also for advising individuals on their susceptibility to particular diseases or certain disorders. (30)

### **Genetic Knowledge, Human Values and Human Responsibility :**

The context in which genetic counselling occurs is rapidly changing. Whereas historically genetic screening has resulted from the diagnosis of an "index case" leading to the identification of carriers, the increasing potential for interventions at genetic level may lead to demand for the screening of individuals at the population level of risk. (1) This has the potential to raise the anxiety of individuals, creating a group of "worried well" and leading to a change of self-image. Whereas much of the medical attention on ethical concern about developments in genetics has been directed towards the implication of gene therapy, Walter has pointed out that in fact the more probable source of harm is genetic screening. (31)

The increase in the predictive potential of genetic screening is likely to have consequences for the extent to which genetic data are used. These data can be used within the context of health care which does not represent an ethical problem. However, these data can also be used outside the framework of care of the individual, in particular, in the domain of employment or insurance. (7,32) Whether genetic data is similar to medical data or not, is a matter of controversy. If it is so, then access to genetic data may result in selectivity and possibility of exclusion from access to work or private insurance on the basis of genetic information. This could have considerable consequences at the level of the individual and of society. (33)

The normative framing of the possible applications of this new knowledge should be taken up from now on. Leclerc et al., proposed few normative directions. In order to counteract the risks related to systematic screening programmes, the decision to resort to screening has to be made individually, in

the context of the patient - doctor relationship, and strictly for therapeutic purposes. The genetic health care policies must be based on an open conception of man and the recognition of human solidarity, beyond individual genetic differences.

Finally, the researcher's and health care worker's responsibility in this matter has to be taken on in the perspective of a democratic debate. (34) From a Muslim perspective every effort should be taken to protect the Muslim woman and her family from the adverse effects of advanced technology and from improperly planned researches without depriving her of its benefits. (2)

### Gene Therapy:

French Anderson in 1982 introduced the four well known categories of human gene therapy in the scientific literature. (35) This categorization has been acknowledged by many workers as Lebo and Golbus as being helpful to delineate and focus the ethical gene therapy discussion. (36) These four categories are the somatic cell gene therapy, the germ line gene therapy, enhancement genetic engineering and the eugenic genetic engineering.

The somatic cell gene therapy refers to a situation when a genetic defect in the somatic cells or body cells of the patient are corrected. The germ-line gene therapy is when a genetic defect in the germ or reproductive cells of the patient namely the egg, sperm or the early embryo are corrected so that the offsprings of the patient would not suffer from this defect. The enhancement genetic engineering is when a gene is being inserted in order to try to enhance or improve a specific characteristic as increasing the height. The fourth human gene therapy is eugenic genetic engineering when genes are inserted in order to try to alter or improve complex human traits that depend on a large number of genes as well as extensive interactions with the environment such as personality, character, intelligence or others. (35)

Other workers as LeRoy Walters have suggested that there are really five basic categories. He subdivides enhancement genetic engineering into somatic cell

enhancement genetic engineering and germ-line enhancement genetic engineering. (37)

Germ-line therapy presents an unsolvable tension between the beneficence intended in the complete and permanent removal of a genetic defect and the adverse dangers that such a treatment might impose on the embryo and on that embryo's future offspring. Some feminists also center the argument upon the likely outcomes for the women "who bear them". (38) Gene-line gene therapy thus poses the possibility of harm not only to "future persons", but also to women who must bear the financial, emotional, physical, psychological and perhaps genetic risks of the treatment.

The core of concern about germ line gene therapy is "the slippery slope" leading to attempts at germ-line enhancement that causes all of us to question whether a strict prohibition at the germ-line might not be the safest course. As long as we are able to clearly distinguish therapy from enhancement engineering, some workers would seem to support germ line gene therapy. However the line between ethical and unethical genetic intervention is clearly to be sought in the distinction between what is therapy and what is not therapy. (39)

There is no doubt that the rather general approval which somatic cell gene therapy receives, does not exist regarding germ-line therapy. It might even look as though there were almost a consensus to the contrary, that is about the non-acceptability of germ-line therapy in the European medical research councils. (40)

The work group on human gene therapy at the Inuyama CIOMS conference of 1990 goes on to say that "germ-cell therapy should be broadly discussed before it is upon us, although it is not an immediate prospect. Before germ line therapy is undertaken, its safety must be very well established, for changes in germ-cells would affect the descendants of patients". (41)

De Wachter in his conclusion on the topic of ethical aspects of human germ-line gene therapy stated that ethics has not been able to solve the dilemmas of germ-line gene therapy. On the one hand, it is difficult to reject summarily all forms and types, past, present and future, of human germ-line gene therapy,

specially in cases where only germ-line therapy would do the therapeutic job. (40)

Genetic manipulation is desirable to remedy genetic defects. Serious ethical questions begin to arise at the borderline cases when the aim of genetic manipulation shifts from therapy to the creation of new human types.(42) The importance of clear moral guidelines in the conduct of gene therapy is understood by reports of secretive use of recombinant DNA and cloning techniques on patients in otherwise enlightened nations. These unacceptable researches are initiated by the perception to stay ahead of international competition in biotechnology and to avoid strong public protest. The slippery slope of the utilitarian is a grave and certainly is a danger when business and utility rather than ethics, drive the application of medical knowledge scientific or otherwise. (43)

From a Muslim perspective, human gene therapy should be restricted only to therapeutic indications. Somatic cell gene therapy is encouraged as it involves remedy and alleviation of human sufferings. However, enhancement genetic engineering or eugenic genetic engineering would involve change in the creation of God which may lead to imbalance of the whole universe and should be prohibited. (33) Gene therapy to manipulate hereditary traits such as intelligence, stupidity, stature, beauty, ugliness, sterility or fertility is a serious attempt as it might imbalance the life of man. (11)

If ever germ line gene therapy is practiced it should be solely restricted to therapeutic purposes. A pre-requisite for this application is that scientists should be absolutely certain that such manipulation will not affect the descendants of patients, in an unforeseen pattern which is, with the present state of the art, almost impossible. (33)

Certainly with the expected wider application of human genome therapy in future there are several ethical questions to be answered. Some of these questions are:

- 1- What would be the criteria for approval of human gene therapy protocols?
- 2- How should we select patients without discrimination?



- 3- What would be the social control mechanism?
- 4- How is it possible to respect medical confidentiality and patient's autonomy?
- 5- The pressing question of allocation of resources, specially in developing countries.

More extensive ethical debate is required on these extremely sensitive ethical issues. When these issues are discussed one must bear in mind the differences in the ethical percepts of different societies. (33)

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