MEDICAL GENETIC ETHICS, ISLAMIC VIEWS AND CONSIDERATIONS IN IRAN

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ABSTRACT

The rapid progress of science and technology, including genetic research and technology has been led to new hopes in the treatment of some genetic conditions and diseases. But these developments have also raised ethical and societal concerns in different communities. Certainly, medical genetics knowledge should be applied so, we have to maximize its benefits and minimize any harm. In recent decades, many attempts have been performed by scientists, ethicists, jurisprudents and lawyers for compiling international and national guidelines for regulation and legislation in this field.

For compilation of this article, we searched some comprehensive electronic databases and some valid English and Farsi books and journals. In this intensive review, we intend to provide a basic knowledge about genetic ethics for health care professionals in order to facilitate their decision-making in clinical practice.

There are various ethical issues related to medical genetics that we reviewed in this paper in brief. These key issues do need attention and urgent resolution universally. We also reviewed Islamic view of points in this regards and finally we addressed the status of genetic ethics in our country, containing new national guidelines in this field.

Keywords: Medical ethics, Medical genetic, Genetic ethics, Islam, Iran

INTRODUCTION

The ever-increasing progress in science and technology has been accompanied by a parallel success in biotechnology and medical genetics. The rapid advances in genetic research and technology over the last few decades have provided the genetic testing tools for a number of disorders and have led to new hopes in the treatment of some genetic conditions and diseases. Indeed, these developments have also raised ethical and societal concerns about how emerging technologies will be implemented, and how their implementation will impact different communities. Ethical values and social concerns must help us to know how medical genetics knowledge will be applied so that we could maximize the benefits and minimize any harm. In recent decades, many attempts have been performed by scientists, ethicists, jurisprudents and lawyers for compiling international and national guidelines for regulation and legislation in this field. Genetic testing is subject to a wide range of national and international guidelines, recommendations, declarations, reports and regulations (1). In this way, the Universal Declaration on the Human Genome and Human Rights (1997), and the International Declaration on Human Genetic Data (2003) have been compiled by United Nations Educational, Scientific and Cultural Organization (UNESCO) (2, 3). World Health Organization has also addressed this issue in recent decade (4-8). Regional office for the Eastern Mediterranean of World Health Organization (WHO) in 26th meeting of Regional Consultative Committee (RCC) in 2002 discussed ethical issues related to gene manipulation and its effects on health care delivery (7). Moreover, different countries have written and conducted some national regulations (9-13). The social values and norms of different cultural environments necessitate the need for development of ethical standards and codes.

METHODS

In this paper we aimed to review main issues of medical genetic ethics and discuss Islamic jurists' opinions about its critical debates. We will also intend to state the situation of genetic ethics in Iran. For compilation of the article, we obtained the data by means of searching through computerized databases in PubMed, IranMedex, and Ovid sources using keywords such as genetic ethics, genetic test, gene therapy, etc in combination with Islam and Iran. Then we supplemented our searches via checking the reference lists of the papers and searching relevant journals. We also referred to some valid English and Farsi books. This intensive review is aimed at providing health care professionals a basic knowledge about the main issues in medical genetic ethics in order to

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facilitate making their decision within clinical practice.

Main Ethical Issues

There are various issues related to medical genetics which can be related to genetic information merely; or to genetic manipulations or therapies. Some critical ethical challenges arising in medical genetics are listed in Table 1. These key issues would need necessary global attention and urgent resolution.

Pre-Natal Diagnosis (PND) and Pre-Implantation Genetic Diagnosis (PGD) are predictive presymptomatic testing to establish fetus's genetic predisposition to a particular disease. Families who are likely to have a child with genetic conditions such as Down syndrome or spina bifida can profit from antenatal genetic screening. There are several aspects of genetic testing that may lead to ethical dilemmas (14). Serious psychological damage, stigmatization in social life, discrimination in employment, life and health insurance are some risks of genetic testing. Genetic labeling could be a significant form of morbidity. However, advantages of antenatal screening consist of a reduction in births of children with burdensome conditions, reduced risks to mothers, reduced public costs of care, and our greater freedom of choice. Prenatal genetic screening is commonly used to identify high risk pregnancies regarding birth defects, such as neural tube defects and genetic conditions like "Down syndrome" (14). However, for some hereditary disorders, PND remains controversial, particularly when the diagnosis leads to a decision of pregnancy termination for a disease that, unlike Tay-Sachs disease, is not definitely an untreatable, fatal disease of infancy (15). Abortion in genetic disorders of fetus is a critical debate in genetic testing.

Another growing clinical application of genetic testing is the identification of genetic predisposition to disease in order to guide early intervention and preventive care. This type of genetic testing is another field in which ethical dilemmas frequently arise. In some disorders (such as Huntington disease, breast or ovarian cancer), existence of a mutant allele may cause a disabling disease later in life, but testing for some conditions for which there are no treatments have the potential to cause psychological harm, stigmatization, and discrimination. Genetic testing for Huntington’s disease (a progressive motor and cognitive disorder with onset in midlife) is one example (14). Although identifying carriers could have benefits but potential harms could arise from testing. Informed consent for testing, privacy of personal genetic information, and providing consultation and treatment facilities are important headings of ethical issues.

Considering these issues, International Declaration on Human Genetic Data has defined accepted purposes of genetic testing (3). According to the declaration, human genetic data and human proteomic data may be collected, processed, used and stored only for the purposes of: (i) diagnosis and health care, including screening and predictive testing; (ii) medical and other scientific research, including epidemiological, especially population-based genetic studies, as well as anthropological or archaeological studies, collectively referred to hereinafter as “medical and scientific research”; (iii) forensic medicine and civil, criminal and other legal proceedings, taking into account the provisions of Article 1(c); (iv) or any other purpose consistent with the Universal Declaration on the Human Genome and Human Rights and the international law of human rights (3, Article 5).

In recent years, interest in application of genetic data in workplace by employers or insurance companies to identify genetically prone employees has been increased. These measures have led to major concerns by the public and some legislators in some countries (16). Several states in the USA have passed genetic privacy and genetic antidiscrimination laws (16).

A debate is ongoing in different communities on "designer babies" or "transgenic man". Prenatal selection for some desirable alleles and genes for complex traits (such as personality, intelligence, and physical characteristics) and sex selection have arose considerable discussions worldwide. Although sex selection for reduction of the risk of sex-limited or x-linked diseases is justifiable, there are serious ethical and social debates about sex selection only for parent's request based on socio-cultural tents or economic reasons, such as one sex superiority over other.

Additional problems may arise from genetic screening programs. The ultimate objective of genetic screening is to improve the public health but there may also be unintended negative consequences. Disregarding of standards of informed consent, risk of overt or implied compulsion, and contingency of unauthorized access to samples or data are some ethical issues which require appropriate attentions and supervisions (15).

In medical genetic ethics, a great deal of importance is placed on the individual informed consent. Human genetic data have a special status on account of their sensitive nature since they can be predictive of genetic predispositions concerning individuals and the power of predictability can be stronger than assessed at the time of deriving the data; they may have a significant impact on the family, including offspring, extending over generations, and in some instances on the whole group; they may contain information that its significance is not necessarily known at the time of the collection of biological samples; and they may have cultural significance for people or groups (3).

Privacy of genetic information is a central ethical principle in medical genetics. International declarations endeavor to protect the privacy of individuals and the confidentiality of human genetic data linked to an identifiable person, family, or an ethnic group (2,3). Most ethicists agree that, while confidentiality is important, there are situations in which confidentiality can be broken. The most common example involves a duty to warn; e.g., a pilot at high genetic risk of heart failure.

Genetic engineering has been the inspiration for exciting science fiction for many years. Since genetic engineering is regarded as having the potential to manipulate human nature itself; it encapsulates people's fears regarding future abuses of science (17). Main genetic engineering issues consist of gene therapy (somatic cell and germ cell), eugenics, stem cell research and cloning, pre-implantative intervention and selective abortion.

There are significant ethical issues in the field of somatic cell manipulation such as the need to balance any potential benefits and harms, the safety and effectiveness, selection of subjects, informed consent, and protection of privacy and confidentiality. Germ line manipulation is a serious controversy worldwide. Gene therapy that involves human germ line cells is not ethically acceptable by most ethicists and is not permitted by existing official guidelines.

Eugenics involves improving the gene pool by elimination of defective genes, and improving attributes such as intelligence and personality. There are historical unethical experiments such as involuntary sterilization in USA (18) in order to breed a "*superior race*" in the first half of the 20th century. Currently, eugenic genetic engineering for selection against personality, character, formation of body organs, fertility, intelligence and physical, mental and emotional characteristics is prohibited in almost all countries. An area of interest is the realm of transgenics for the purposes of treatment. The most common use of transgenic technology is in xenotransplantation (19).

Stem cell research and cloning are two subjects that have raised a series of ethical and public-policy questions that are now being confronted by multiple international organizations, nations, cultures, and religious traditions. Key ethical issues facing in these fields consist of human dignity and moral status of human embryo, time of beginning of life, the destruction of pre-implantation blastocysts, slippery slope of dehumanizing practices, justice and resource allocation (20). There are substantial debates regarding the specific stage that dignity is conferred in development (conception, primitive streak development, implantation, ensoulment, or birth).

There are various challenges about genetic tissue banking that are likely to come from the complex organizational, social, political, and ethical aspects of this subject. Concerns about subjects' rights, informed consent, privacy, and ownership of genetic material require attention in the development of DNA banks (21). Adequate anonymization, consent and protection of the samples must be considered in research banks (19).

Questions also arise about patenting of life forms, genes and various other human proteins (16). Ownership of DNA and patenting has been issued in the world for genes and gene sequences since bringing up Human Gene Project (HGP). This issue and related ethical challenges is also discussed by World Health Organization recently (8). Other societal concerns about medical genetics include fairness in the use of genetic information, reproductive decisions and reproductive rights, conceptual and philosophical implications, safety and environmental issues, and the commercialization of products including property rights and accessibility of data and materials (22). There are also other questions related to social implications in choices for marriage partners (23) and assisted reproduction techniques.

Islamic Perspective

There is no conflict between science and religion faith in Islam. Also, the performance of research on human subjects is Islamically acceptable, a researcher should comply with the framework of Islamic law in any research that he/she undertakes (24). The incidence of genetic diseases in the Islamic world is high because of social and other factors that promote consanguinity (25). Therefore, genetic services should be made a component of public health care systems. Muslim religious scholars, research scientists and policy makers should collectively and continually ponder over these questions and take steps to effectively deal with the situation (23,26). It is duty of Muslim ethicists and jurists to analyze new modern issues of medicine and biotechnology and inform Muslims about the religious and ethical approaches regarding such issues. Some ethical issues associated with medical genetics have been dealt in some details by Muslim jurists of the sunni and shi'a schools.

Since Islam calls attention to pain alleviating and disorder healing, there is no serious ethical debate against therapeutic strategies applied for prevention, delaying onset, or carrying out appropriate care for genetic disorders (25). Genetic testing is not prohibited in Islam, and so prenatal and presymptomatic testing are acceptable if the aim of them would be prevention, delaying onset of diseases, improvement of qulity of life, or diseases treatment. Genetic screening for detection of genetic abnormalities and possible cure of birth defects, and so genetic counseling would be acceptable (27,28).

In Islamic communities some components of genetic counseling and testing are sensitive points and the transfer from one social context to another needs careful consideration (25). For example; prenatal testing is faced with some limitations, although it is allowed in Islam (25). Although therapeutic abortion would be permitted before 120 days counted from conception under special circumstances (29,30) elective abortion is generally unacceptable (30,31).

Gene therapy should be used solely for therapeutic purposes (32) and it should not be used to promote destructive purposes. Somatic gene therapy and replacement of defective genes is acceptable from viewpoint of Islamic jurisprudence (27) but germ line gene therapy is prohibited. It has potential of altering the genetic make up and other consequences for the next generations, and there is enough knowledge about its complications and risks (7). Meanwhile, based on opinion of most Muslim jurists, gene therapy that has effect on the future progeny is impermissible (33).

Gene manipulation other than therapeutic approaches is not allowed in Islam. Hence, eugenics and dysgenics could not be performed in human according to majority of Muslim jurists opinions. (27,32). However some jurists permitted human fetus gene manipulation for skin color change, intelligence improvement and etc in current years (30). Surgeries to treat congenital or acquired deformities to restore normal shape or function of an organ are also permissible (33). Sex selection is not acceptable except for medical reasons in gender related diseases. Islam teaches contented with the will of God (27). Similarly, Islam is not in agreement with 'designer babies' or 'transgenic man'. The issue of 'plying God' and altering creation through gene therapy, particularly for cosmetic reason, and unnecessary changes in appearance has been considered in some "Fatwas". The majority of Muslim jurists have permitted this if an abnormality accompanied with physical or psychological harms. Human equity despite differences in race, color, gender, and other physical characteristics is emphasized in Islamic teachings. We would read in Holy Qur'an that: "*Oh mankind! We created you from a single (pair) of a male and a female, and made you into nations and tribes, that you may know each other (Not that you may despise each other); 49/13*".

The Islamic Figh Academy (IFA), a subsidiary organ of the Organization of the Islamic Conference (OIC) affiliated to the world Muslim league (WML) addressed the ethical guidelines of genetic engineering in its 15th session in 1998. Based on recommendations of the OIC, it is categorically prohibited to use genetic engineering to attain evil aims or to reach prohibited means (33).

The use of genetic engineering in agriculture and animal breeding under necessary precautions are permitted (30). However, producing Genetically Engineered Micro-organisms, foods and transgenic animals or plants could be permitted and performed from Islamic perspective (30). In plants and animals' gene manipulation, environmental risks must be considered and eliminated (30). Genetic changes and related experiments in animals are permitted in Islam but additional harms and torture must be avoided (30).

According to inevitable consequences of human reproductive cloning, it is prohibited due to majority of Muslim reference decrees (34). Stem cell research and cloning for therapeutic purposes is permissible (27,30,35-37) with full consideration and all possible precautions in pre-ensoulment stages of fetus development (34, 38).

Medical Genetics Ethics in Iran

Iran, a large country with a population of 67 million, represents a highly heterogeneous gene pool and mutation spectrum due to the geographical, cultural and ethnical diversity (39). Iran is a member of Genetic Research Network established in Eastern Mediterranean Region in 2004 (40,41). The number of centers for genetic research in Iran has been increased in recent years and an emphasis on ethics has been voiced by medical and religious authorities (42-49). Compilation of a strategic plan for medical ethics activities carried out in 2002 by the Research and Technology Deputy of Ministry of Health and Medical Education (43). Currently, National and Regional Ethical Committees in universities and research centres supervise genetics and other medical researches for protection of human subjects. Any discussion of ethical issues needs to take place within a framework which incorporates the principles of justice, autonomy, beneficence and non-maleficence (22); despite the fact that Iran, as an Islamic country, has own interpretations about these principles that we would explain in other article. In two studies (50, 51), Dr. Farhud et al. have investigated the point of views of physicians, nurses, midwives and medical students about principles of medical genetics. They concluded that there is highest agreements on the principle of proportionality (88–91%), beneficence (75–89%), followed by autonomy (72–80%) and justice (70–83%) (50). Beneficence, according to the views, was the main look out for making decision (51).

Currently there is no absolute restriction on genetic research in Iran, however moral principles and ethical codes must be completely followed. The "*National Ethical Guidelines of Medical Research*", including genetics research has been compiled recently. Based on the guideline, genetic researches are permissible only if their purposes would be:

1. To diagnose, classify or screen genetic diseases
2. To define genetic predisposing factor of a disease before it appears, if there is an efficient way to prevent or reduce the complications.
3. To provide consultation for couples about genetic risk factors of their offspring.
4. To alleviate, prevent or cure diseases and not for eugenics
5. Forensic medicine
6. Population based genetic research regarding scientific and ethical principles

According to the guideline, prenatal diagnosis is permissible only if it is concerned with mother or fetus health. It should be mentioned for parents that prenatal diagnosis does not guarantee the "health of baby". The probable risk for mother and fetus should be described for parents.

Eugenic researches are not permissible based on the national guideline and sex selection is allowed only in X-linked disorders. Human reproductive cloning is also prohibited. Stem cell research is permissible to obtain embryonic and adult stem cells, regarding scientific and ethical principles. But researches on residual embryos could be conducted only after parent's consent.

Iran's Muslim shi'a religious leaders have issued decrees authorizing animal cloning but banning human reproductive cloning. Consequently, Iranian researchers of Royan Institute reported the derivation of a new embryonic stem cell line (Royan H1) from a human blastocyst two years ago(52). In addition, Iran hopes to celebrate the birth of cloned sheep in the near future (53).

Abortion is a main debate in the subject of prenatal genetic testing. There are many different cultural perspectives about therapeutic abortion and the time that human life begins. Therefore, there isn't universal agreement on the issue of pregnancy termination following prenatal diagnosis. The parliament of the Islamic Republic of Iran approved a new act on abortion "21 June 2005" (54). Previously, religious scholars had been allowed abortion in untreatable and genetic disorders with 3 criteria; definite diagnosis, before 4 months of gestation, and unusual problems for family. Under the new law, a pregnancy can be terminated within the first four months of pregnancy if the fetus is mentally or physically handicapped, or where the mother's life is likely to be in danger (54). Three specialists must confirm the problem. Legal Medicine Organization has defined 51 fetal and maternal disorders, including some genetic disorders that could be considered in this act. Twenty-nine indications are fetal abnormalities and disorders such as Osteogenesis Imperfecta, Osteochondrodysplasia, Osteopetrosis Infantile, Alpha-thalasemia, Trisomy of chromosomes 3,8,13,16,18, etc.

CONCLUSION AND RECOMMENDATION

Cultural differences in various countries and ethnic populations should be considered and reflected in the recruitment, and in the structuring and comprehension of the genetic ethics rules. Ethics education for scientists and general population are essential for better mutual understanding of ethical challenges in the society. General health care providers currently do not have expertise in clinical genetics or in molecular genetic testing. Widespread education for health professionals in genetics, risk assessment and behavior change is needed across the globe (55). Clinicians must be involved in considering ethical questions associated with any genetic tests. Addressing these questions require a continuing dialog and cooperation between physicians, researchers, religious scholars in our country and within other Islamic countries.

According to International Declarations on medical genetics, compiling culturally-adopted national guidelines, as a necessary action, should be followed by scientists, ethicists, jurisprudents and lawyers in all countries of the region. Establishment of a national well-controlled system and appropriate ethical and scientific supervision of medical genetics programs in each country should be enhanced to make sure that the advances in human genetic knowledge and technology are used responsibly, fairly, and humanely. More distinct supervision is necessary for non-therapeutic genetic screening.

Considerable attention should be paid to justice in distribution of genetic advances' benefits and in resource allocation at national and international level. Regarding our mutual believes and ethical values, the necessity of strenghthening the "*Regional Genetic Network*" including an ethical conduct should be considered.

As it stated previously the public also needs to become more acquainted with genetic tests. Improvements in public awareness will alleviate

some of the extensive pre-test education needs that exist currently (55).
With the increasing number of identified genes causing diseases and the existence of genetic variation between different populations in the world, establishment of population- specific DNA banks could provide valuable sources of information and sample for medical genetic research in the field of diagnosis, prevention and hopefully cure of hereditary diseases world-wide, though the ethical values in this field must be precisely respected.

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Table 1. Critical Ethical Issues in Medical Genetics

- **Genetic testing**
    - Prenatal and Pre-implantation Genetic Diagnosis
        - Prenatal Testing, especially for non-disease traits or sex
        - Abortion (therapeutic and selective)
    - Pre-symptomatic testing in children and adults
        - Testing for genes that predispose to late-onset disease
        - Testing children for a carrier state
    - Genetic Screening
- **Privacy of Genetic Information**
    - Stigmatization and privacy
    - Misuse of Genetic Information
        - Discrimination in employment
        - Discrimination in life insurance underwriting
        - Discrimination in health insurance underwriting
- **Genetic engineering**
    - Gene therapy and Gene transfer research
    - Eugenics and Dysgenics
    - Stem cell research and Cloning
    - Sex and traits selection before birth
- **Banking DNA**
- **Patenting of Human Genes**

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