

Ethical guidelines in genetics and genomics

An Islamic perspective

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ABSTRACT

We are at a time of unprecedented increase in knowledge of rapidly changing technology. Such biotechnology especially when it involves human subjects raises complex ethical, legal, social and religious issues. A World Health Organization expert consultation concluded that "genetics advances will only be acceptable if their application is carried out ethically, with due regard to autonomy, justice, education and the beliefs and resources of each nation and community." Public health authorities are increasingly concerned by the high rate of births with genetic disorders especially in developing countries where Muslims are a majority. Therefore, it is imperative to scrutinize the available methods of prevention and management of genetic disorders. A minimum level of cultural awareness is a necessary prerequisite for the delivery of care that is culturally sensitive, especially in Islamic countries. Islam presents a complete moral, ethical, and medical framework, it is a religion which encompasses the secular with the spiritual, the mundane with the celestial and hence forms the basis of the ethical, moral and even juridical attitudes and laws towards any problem or situation. Islamic teachings carry a great deal of instructions for health promotion and disease prevention including hereditary and genetic disorders, therefore, we will discuss how these teachings play an important role in the diagnostic, management and preventive measures including: genomic research; population genetic screening (pre-marital screening, pre-implantation genetic diagnosis; assisted reproduction technology); stem cell therapy; genetic counseling and others.

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We are at a time where there is a need to exercise power to ensure the health of populations and at the same time to avoid potential abuses. How are we to ensure that all populations benefit from recent advances in treatments, therapies, and technologies?¹ Islam has its roots in seventh century Arabia; however, it is not an "Arab" religion. In fact, out of the 1.5 billion Muslims in the world, <10% of Muslims are Arabs.² The majority of Muslims worldwide are Asian or African. More than 50% of North American Muslims are indigenous, usually Black, with an increasing number of Caucasians and Latino converts as well.³ Islam has a moral code as well as a civil law with a unifying ethical framework. A universal foundation of practices and beliefs creates a monotheistic culture, the aim of which is to create

peace in one's self, family, and society by actively submitting to and implementing the will of God. Various cultures further refined this culture based on their inclinations and sensitivities. Some differences among Muslims are attributable to differences of opinion by various schools of jurisprudence,⁴ (of which there are 7 major ones: Hanbali, Maleki, Hanefi, Shafe'i, Ja'fari, Zaidi in Yemen, and Abhadi in Oman). Others are not Islamic but ethnic, and may even violate Islamic norms.³ Between the 6th and 10th days of Rabi 1401 Hijra (January 1981), an international conference on Islamic Medicine was held in Kuwait, to mark the advent of the 15th century of Hegira. One fruitful outcome of this meeting was the Declaration of Kuwait, which deals with the ethics of medicine in the light of Islamic law.⁵

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What is bioethics? ***Bioethics in Islam?*** Medical practice and research involving human subjects raises complex ethical, legal and social issues. Investigators sometimes find that their obligations with respect to a research project come into conflict with their obligations to individual patients. The ethical conduct of research rests on 3 guiding principles: respect for persons, beneficence, and justice. Respect for persons underlies the duty to obtain informed consent from study participants. Beneficence demands a favorable balance between the potential benefits and harms of participation. Justice requires that vulnerable people not be exploited and that eligible candidates who may benefit from participation not be excluded without good cause. Studies must be designed in a way that ensures the validity of findings and must address questions of sufficient importance to justify the risks of participation.⁶ Islamic bioethics derive from a combination of principles, duties and rights, and, to a certain extent, a call to virtue. In Islam, bioethical decision-making is carried out within a framework of values derived from revelation and tradition. It is intimately linked to the broad ethical teachings of the Qur'an and the tradition of the Prophet Mohammad (Sunna), and thus to the interpretation of Islamic law (Sharia'ha). In this way, Islam has the flexibility to respond to new biomedical technologies. Islamic bioethics emphasizes prevention and teaches that the patient must be treated with respect and compassion and that the physical, mental and spiritual dimensions of the illness experience are taken into account.⁷ Development of Sharia'ha in Islam over the ages has also required Ijtihad the law of deductive logic. Where appropriate, consideration is also given to maslaha (public interest) and urf (local customary precedent).⁸ The 4 main concerns of Islamic ethics are similar to Western ethical systems: autonomy, beneficence, non-maleficence, and justice.⁹ Islamic law (Sharia'ha), is in spirit dynamic and flexible, exemplified by the idea that "necessity renders the prohibited permissible".¹⁰

Genetics and genomics in developing countries.

Ensuring that advances in genomics are applied to health improvement of people living in developing countries is an important contemporary challenge. In the near term, such advances are likely to alleviate infectious diseases, with longer-term benefits envisaged for chronic diseases.¹¹ To insure that benefits are shared by developing countries, attention must be paid to complex ethical, legal, social, religious, and economic issues, as well as public education and engagement. Many of the advances in genomics were made, and in part are owned, by the developed world, which will further widen the equity gap in health between rich and poor nations,¹² which is one of the concerns of the World Health Organization (WHO), which points out in one of its report, that

80% of investments in genomics in 2000 were made in the United States, and 80% of DNA patents in Genomics in the period 1980 through 1993 were held by US companies.¹³ Medical genetics involves the application of genetic knowledge and technology to specific clinical and epidemiologic concerns. Certain ethical and legal responsibilities accompany the flood of genetic knowledge into the current practice of medicine. This is due to its 3 general characteristics of genetic information: the implications of genetic information are simultaneously individual and familial; genetic information is often relevant to future disease; and genetic testing often identifies disorders for which there are no effective treatments or preventive measures.¹⁴ Although there is no single ethical issue that unifies the field of genetics, informed consent, confidentiality and the potential for social harm and psychological distress are issues that physicians involved with testing should understand.¹⁵ Essentially, the principles and components of consent that are generally acceptable in Western countries are also applicable to Muslims, although Muslims (depending on their level of education, background and culture) will often want to consult with family members before consenting to major procedures. Particular care should be exercised when the consent involves abortion, end-of-life issues or sexual and gynecological issues.⁷ The 1989 Children's Act states that age of consent is when a child reaches their sixteenth birthday, or younger, if a doctor deems a child capable of understanding and making decisions. In Islamic law, the age of majority (and hence full autonomy) taken by Shafi School and Hanbali School of jurisprudence is 15 years while Abu Hanaifa and Malik take the age of 18 years. There is a difference between the age of puberty and the age of taking decisions. The Holy Quran stipulates that orphan children should not receive their inheritance except after being tested for their competence in dealing with monetary problems (The Holy Quran 4:6). Hence the age of majority and decision taking could be postponed to 21 years, if the person concerned is still incapable of giving proper decision before that age.¹⁶ In Islamic countries, Genomics research need to be regulated within the context of culture and religion. *The Islamic Jurisprudence Council of the Islamic World League* in Makkah Al-Mukarama, Saudi Arabia regularly hold conferences in situations requiring specialist knowledge (for example, decisions concerning medical practice, or research), the somewhat novel concept of a "consensus edict" (fatwa): an authoritative ruling on a point of Islamic law is preferable. For rulings pertaining to medicine these consensus groups will typically include a broad and diverse representation of Ulema (Islamic Jurists) and specialist, clinicians and scientists from relevant disciplines, the latter responsible for providing the necessary background information. The decision making process is typically transparent with members of the wider community able to scrutinize the arguments

employed and the textual material underpinning these edicts. Counter arguments may be presented, and it is not unusual for 2 or more seemingly contrasting opinions to coexist. In such cases individuals are, in principle, free to choose whichever judgment they find most agreeable, though in practice many will choose to remain loyal to their particular school of thought.⁷⁻⁹ The Islamic Organization for Medical Sciences, (www.islamset.com), based in Kuwait, also holds conferences and publishes the Bulletin of Islamic Medicine. Most Islamic communities, however, would defer to the opinion of their own recognized religious scholars.⁷

Genetic counseling and Islam. Genetic counseling is a field of medicine demanding a comprehensive knowledge of genetics and the management of genetic diseases, as well as its impact on the individual, the family, offspring and the community at large. Islamic teaching encourages counseling. The Prophet Mohammed said: "*Religion (Islam) is sincere counseling and good advice*". The Prophet Mohammed also said: "*The counselor should be trustworthy*". Indeed a counselor cannot be trustworthy unless he or she is proficient in the field in which they are giving advice.¹⁷ Being proficient and knowledgeable in one's field is not enough. The counselor should be considerate and compassionate, and should maintain absolute confidentiality of the person(s) or family involved. Being considerate, kind, merciful, and giving good advice to those who need and ask for is the basis of Islamic ethics in general, and of medical ethics in particular (beneficence). The rule of non-maleficence is exemplified by the Hadith: "Do no harm". The counselor's role is to provide facts on genetic information in plain and understandable language. The counselor should also consider clients' social habits and religion before giving advice. Islam was the first religion to give people full freedom to accept or refute the Islamic creed. God says: "*There should be no compulsion in religion*" (The Holy Qur'an 2:256). A counselor should seek to provide accurate, sincere advice, but should not try to impose it upon the client.¹⁷ A consanguineous marriage is usually defined as marriage between people who are second cousins or closer, but leads to and increases birth prevalence of infants with severe recessive disorders.^{18,19} It is customary in Middle Eastern population, Irish travelers, Zoroastrians, some Jewish communities, and many tribes in sub-Saharan Africa and South East Asia. Although, the customs often perceived to be associated with Islam, in fact is independent of religion. It is estimated that 20% of human population live in communities with preference for consanguineous marriage, and at least 8.5% of children have consanguineous parents.¹⁹ Islamic teaching discourages first-cousin marriages.¹⁷

In 1994 and 1996, the WHO's Regional Office for the Eastern Mediterranean (which covers North Africa and the Middle East, including Pakistan) convened 2 meetings of experts in medical and social sciences to review the place of genetics in medical services in the regions. The participants agreed that consanguineous marriage is an integral part of cultural and social life in many areas, and that attempts to discourage it at the population level are inappropriate and undesirable. They concluded that the development of genetics services is a particularly high priority for such communities.¹⁹

Genomic research and Islam. Genomics provides powerful means of discovering hereditary factors in disease. But even in the genomic era, it is not genes alone but the interplay of genetic and environmental factors that determines phenotype. However, as is true for so much of the application of genomics, ethical, legal, and social issues complicate this era. Unless complex issues regarding the patenting and licensing of gene-based knowledge and techniques are dealt with more successfully than they are today. Another social issue, with particular relevance in the United States, is the understandable concern of many patients that obtaining genetic information important to their health care is not worth the risk of discrimination stemming from the use of such information by potential insurers or employers. Other social issues require our attention if genomic medicine is to benefit our patients. How should genetic tests be regulated? What, if any, are the appropriate uses of direct-to-consumer marketing of genetic tests. How will health care providers and the public distinguish between these and responsible testing services, whether they are available through the Internet or in the hospital? It would be easy to assume that for the foreseeable future the benefits of genomic medicine will accrue only to people in developed countries.²⁰ The benefits of molecular genetics and bio-engineering to Muslims have been discussed by *The Islamic Jurisprudence Council of the Islamic World League* (Organization of Islamic countries) in Makkah Al-Mukarama in its 15th session (11th/07/Hijra/31 October 1998 Gregorian), and they decided: 1) to use genetic engineering for disease prevention, treatment, or amelioration on the condition that such use do not cause further damage; 2) to forbid the use of genetic engineering for evil and criminal uses or what is forbidden religiously; 3) to forbid using genetic engineering and its tools to change human personality and responsibility, or interfering with genes to improve the human race; 4) to forbid doing any research or therapy of human genes except in extreme need, after critical evaluation of its benefits and dangers and after an official consent of the concerned, respecting the extreme confidentiality of the information and human rights and dignity as dictated by Islamic

Sharia'ha; 5) to allow the use of bio-engineering in the field of agriculture and animals, on the condition that precautions are taken not to inflict harm (even in the long term) on humans, animals or vegetation; For DNA fingerprinting, *The Islamic Jurisprudence Council of the Islamic World League* (Organization of Islamic countries) in Makkah Al-Mukarama in its 16th session (21-26/10/1422 Hijra/5-10 January 2002 G) have decided: 1) It is religiously allowed to use DNA fingerprinting on judges' orders and performed in the state laboratories; in forensic interrogations to prove crimes which has no definite penalty in Islamic law (Sharia'ha) (as Prophet Mohammed says "avoid punishment if there is any doubt, as doubt should always be used for the sake of the accused"), this will lead to justice and to safety of the community, as the criminal will be punished and the innocent will be freed from guilt, which is one of the most important goals of Sharia. 2) Deoxyribonucleic acid fingerprinting may be used in lineage (genealogy) only with great caution and confidentiality as the Sharia rules take precedence over DNA fingerprinting. 3) It is forbidden to use DNA fingerprinting in paternity (lineage) disputes, which should not precede the oath of condemnation (the sworn allegation of adultery committed by one's spouse). 4) It is forbidden to use DNA fingerprinting to confirm or refute legally proven lineage; the state should forbid this and inflict punishment, in order to protect people's honor and to preserve their lineage. 5) It is allowed to use DNA fingerprinting in proving lineage on the following conditions: (i) in cases of dispute about unknown lineage, as mentioned by the Islamic scholars because the evidence is either absent or equivocal, and to overcome the vagueness (suspicion). (ii) in cases of disputes over babies in hospitals and nurseries or test-tube babies; (iii) in cases of children lost because of war, accidents or natural disasters, where their family could not be found and; (iv) to identify bodies or prisoners of war.

Population Genetic Screening Programs and Islamic ethics. Population Genetic Screening Programs are public health programs targeted at populations or subgroups identified by their risk category. The goals are the detection or prevention of genetic disorders and birth defects at the population level.²¹ A statement from a WHO expert consultation²² concluded that "genetic advances will only be acceptable if their application is carried out ethically, with due regard to autonomy, justice, education and the beliefs and resources of each nation and community". These screening programs are governed by several ethical principles: including the rights of an individual to access appropriate information and to make choices on participation in the program; avoidance of social stigmatization of persons found to be at increased risk or of those

declining screening; and avoidance of the misuse of information and of discrimination based on the test results. Economic criteria alone cannot be used to justify a screening program.²³

Primary prevention strategies: 1) Control of teratogens. Rubella is virtually eliminated in many countries by vaccinating girls of school age. Syphilis and other sexually transmitted diseases (STD) will not appear if all sexual desires are channeled through marriage as Islamic teachings implies. Fornication, adultery, and sodomy are all harshly punished in Islamic legal code, and religiously they are considered of the greatest sins, that each Muslim should avoid. Any substance that is going to be harmful to the baby (namely teratogen) such as alcohol, smoking, should be avoided as the prophet Mohammed, said: "Do no harm".²⁴ 2) Pre-marital or pre-pregnancy genetic screening. Genetic blood disorders (thalassemia and sickle cell anemia) and Tay-Sachs disease are the groups of disorders where there is most experience and where outcome data are available. The birth rate of children with thalassemia major has fallen by at least 75% in Cyprus, Italy and Greece where national programs promote pre-marital screening and where couples most at risk are identified before their first pregnancy.²⁵

These disorders are transmitted by autosomal recessive mode of inheritance so they are quite common in the Islamic population, namely sickle cell anemia, thalassemias, and glucose-6-phosphate dehydrogenase (G6PD) deficiency, which involves 20-25% of the whole population in Hofuf and Qatif (Eastern province of Saudi Arabia) and Jizan (South West province of Saudi Arabia), the carriers of the trait are one in 4, or one in 5 in the whole community, any carrier will have a high risk of marrying another carrier of the trait.²⁶ The Islamic Jurisprudence Council of the Islamic World League (Organization of Islamic countries) in Makkah Al-Mukarama in its 17th session in 13-17 December 2003 (19-23/10/1424 Hijra) having looked into the legitimacy of pre-marital medical screening of Genetic Blood Disorders, and has decided: First, the marriage wedlock contract is governed by conditions of the Sharia, from which legal consequences follow. Thus, additional conditions, such as enforcing pre-marital medical screening, are not permissible under the Sharia. Second, the Council recommends that governments and Islamic institutions spread understanding of the importance of pre-marital genetic tests and encourage their use. They should facilitate such tests for those who wish to use them, while ensuring confidentiality so the results are not revealed except to the persons concerned. Pre-pregnancy genetic screening could only be carried out if a genetic disorder is known in a family, and the mutation for such disorder is already known. Population wide pre-pregnancy carrier screening is possible, if the carriers' mutations are known in the

population for common genetic disorders such as Tay-Sachs disease in the West. We have some experience with carrier screening for some of the common disorders in certain families in Saudi Arabia, for which pre-pregnancy screening is possible.²⁷⁻²⁸

Secondary prevention strategies. The aims of such screening programs are the early diagnosis of genetic disorders with a view to preventing or ameliorating their effects. Inborn errors of metabolism (IEMs) and other inherited Mendelian disorders are common in Saudi Arabia and throughout the Middle East, presumably because of the relatively high rates of consanguinity.²⁹ Twenty percent to 25% of all marriages in Saudi Arabia are first cousins, another 20-25% are second cousins marriages and 15-20% are family related, with a total of 60-65% of consanguineous marriages.³⁰

Even in segregated communities, IEMs are estimated to account for as much as 20% of disease among full-term neonates not known to have been at risk and may affect as many as one in 5000 live births.³¹ Many of the IEMs carry serious clinical consequences to the affected neonate or young infant, including mild to severe mental retardation, physical handicap, and even fatality. Although early diagnosis for some of these disorders has proven very effective in treatment or management, neonates are screened for only a handful of diseases, even in the developed world.³² As Islamic bioethics emphasizes the importance of preventing illness, such an important preventive measure to prevent mental handicap in children is highly recommended by Islamic jurists.

Prevention based on reproductive options. Reproductive options which are ethically approved by Western standards vary according to the condition for which an individual is being screened and include pre-natal diagnosis, pre-implantation diagnosis, and sperm or egg donation, the avoidance of further pregnancy, or adoption.

1) Contraception and sterilization. In Islam it is acceptable to use temporary means of contraception, if the couple is agreeable, and if no harm is likely to result. However, sterilization is not acceptable, unless the health of the mother would be endangered by pregnancy. However, in the situation where a couple already had 2 or 3 congenitally-affected children and a lesser number unaffected, then they might choose sterilization. In such a case they would find support from at least some Islamic jurists.^{17,33}

2) Adoption. Adoption is not allowed in Islam, though caring for orphan or children of unknown parents is encouraged and considered as a charity and a great act of worship. However the lineage of the child should be kept to his biological parents.

The Holy Qur'an says: "God did not make your adopted ones your sons" (The Holy Quran 33:4).^{17,24,33}

3) Donation of a sperm, ovum or pre-embryo, or motherhood surrogacy. Artificial insemination by a donor sperm, or egg donation, are all out of bounds in Islamic law. Procreation in Islamic law is limited to husband and wife, during the existence of matrimonial bondage. If divorce or death of a spouse occurs no procreation will be allowed, including surrogacy.^{17,24,33} A November 2000 workshop organized by the International Islamic Center for Population Studies and Research, Al-Azhar University, Cairo, Egypt, considered use of assisted reproduction technologies (ART) in the Islamic world. The same above conclusions were drawn, including no embryo transplantation after husband death.³⁴

4) Pre-implantation diagnosis. Pre-implantation genetic diagnosis (PGD) was introduced at the beginning of the 1990's as an alternative to prenatal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a gender-linked genetic disease.³⁵ Pre-implantation genetic diagnosis is an early form of prenatal diagnosis, where in vitro fertilization is carried out. The zygotes are grown to 8 cell stage (morula stage), embryos created in vitro, are analyzed for well-defined genetic defects; only those free of the defects are replaced into the womb. The technique is used mainly in 2 broad indication groups. The first group are individuals at high risk of having a child with a genetic disease namely carriers of a monogenic disease or of chromosomal structural aberrations, such as translocations. The second group are those being treated with in-vitro fertilization (IVF), who might have a low genetic risk but whose embryos are screened for chromosome aneuploidies to enhance their chance of an ongoing pregnancy.³⁵ The workshop organized by the International Islamic Center for Population Studies and Research, Al-Azhar University, Cairo recognized the importance of PGD, but was guarded about its use on non-medical grounds such as gender-selection or family balancing, considering that each case should be treated on its own merits. Gender selection technologies have been condemned on the ground that their application is to discriminate against female embryos and fetuses.³⁴ For some diseases, PGD but not prenatal diagnosis can be defended from an ethical point of view. In non-disclosure PGD, which has been described for Huntington's disease but could also be applied to other late-onset diseases, patients do not wish to know their carrier status but want to have disease-free offspring.³⁶ Another new indication for PGD involves the selection of embryos, according to their HLA type, so that a child born out of a PGD cycle can be a stem-cell donor for a sick sibling.³⁷ The use

of PGD to diagnose risk of late-onset diseases (such as Huntington's disease and Alzheimer's disease) and to search for genes that predispose for cancer (BRCA1, BRCA2, Li-Fraumeni, neurofibromatosis 1 and 2) is also ethically debatable.^{38,39} Finally, several reports have been published on the use of sexing for social reasons and have provoked mixed reactions.⁴⁰ In Saudi Arabia, PGD is carried out for carriers of a monogenic diseases or of chromosomal structural aberrations, such as translocations, with good results.⁴¹

5) Pre-natal diagnosis. A number of ethical considerations arise with regard to screening for, detecting, and managing fetal anomalies. The ethical principle of beneficence gives rise to a duty of the obstetrician to provide emotional support when needed in relation to screening, confirmatory testing, giving bad news, making abortion decisions, making management decisions after viability, and dealing with the grieving process. Other issues involve ethical decision-making, such as deciding what recommendations to make concerning management of fetal anomalies after viability. The ethical principle of autonomy creates a duty of the obstetrician to help the pregnant woman make informed management decisions based on her values, religion and goals.⁴² Human life begins at the time of ensoulment, which is stated in the Hadith (Sayings of the prophet Mohammed, to be at 120th day from the moment of conception, which is equivalent to 134 days from the last menstrual period (LMP) used by obstetricians). Prior to that moment the embryo has sanctity, but not reaching that of a full human being.²⁴

Each of you will have had his created existence brought together in his mother's womb, as a drop (nutfa) for 40 days, then a leech such as clot (alaqa) for the same period, then a piece of flesh (mughda) for the same period, after which God sends the angel to blow the spirit (ruh) into him (Hadith: Sahih Al-Bokhari and Moslim).⁴³

The fatwa number 4 of *The Islamic Jurisprudence Council of the World Islamic League* (Organization of Islamic Countries) at its 12th session (15-22/07/1410 Hijra/10-17 February, 1990) in Makkah Al-Mukarama, agreed by a majority vote to allow for the option of abortion under certain specific conditions. The fatwa determined that an abortion may take place only if a committee of specialized, competent physicians has decided the fetus is grossly malformed, and that its life would be a calamity for both the family and itself. The malformation must be untreatable, unmanageable and very serious, and the abortion may only be carried out prior to the 120th day of conception (computed from the date of fertilization, not the last menstrual cycle). On the basis of this fatwa, abortions of serious congenital disease are carried out in the hospitals of Saudi Arabia.

New treatment options. Many recent developments in the new genetics have raised ethical dilemmas that have been extensively discussed by medical professionals and ethicists. However, although the moral responsibilities of clinicians and researchers in contemporary biomedicine are reflected upon exhaustively, much less attention has been paid to the moral responsibilities and vulnerabilities of potential patients.

1) Cloning and stem cell research. Cloning is the production of 2 or more beings that are complete genetic copies of one another. Currently, the international community agrees that human cloning for reproductive reasons should not be attempted. The rationale cites safety considerations in view of the many difficulties and defects reported in the cloning of animals.⁴⁴ Others maintain that cloning might be ethically acceptable under certain conditions, for example, if it were the only way for couples with fertility difficulties or a genetic disorder to have a healthy genetically related child.⁴⁵

Issues in public policy on cloning overlap somewhat with general stem-cell matters but have additional dimensions. Prohibition of cloning for reproductive reasons is directed at prevention of the birth of children who are genetic copies of already existing individuals. Legislation on cloning for research, however, deals mainly with development of stem-cell lines through somatic cell nuclear transfer (SCNT), thus raising issues about a specific type of stem-cell research.⁴⁵ In late 2003, 2 international bodies were unable to resolve disagreements that involved bioethical issues. First, the United Nations General Assembly failed to pass a treaty on reproductive cloning because of insistence by some countries that the treaty include a ban on cloning for research. Second, the European Union (EU) failed to agree on conditions for funding stem-cell research because of the diversity of views and policies of the countries of the EU.⁴⁵ The Islamic Jurisprudence Council of the Organization of Islamic countries in Jeddah in its 10th session (23-28/02/1418 Hijra/28 June-3 July 1997 G) explored all the research papers and recommendations of the 9th Medical and Fiqh Seminar held by the Islamic Medical Organization in Casablanca, Morocco, in collaboration with the Council and others (14-17 June 1997 G), declared Decree number 100/2/D10 stating: 1) Human Cloning is forbidden in any method that leads to human reproduction. 2) It is forbidden in all cases to introduce a third party into marriage, be it an egg donor, a surrogate womb, a sperm donor, or a cloned cell. 3) It is permissible to use genetic engineering and cloning in the fields of germs, microorganisms, plants, and animals, following legitimate rules which lead to benefits and prevent harm. 4) All Muslim countries are called upon to formulate the necessary legislation to

prevent foreign research institutes, organizations and experts from directly or indirectly using Muslim countries for experimentation on human cloning or promoting it. 5) Specialized committees should be set up to look into the ethics of biological research and adopt protocols for study and research in Muslim countries. 6) Biological and bioengineering research institutions (other than cloning research) should be supported and established, according to the Islamic rulings, so that the Muslim world will not be dependent on others in this field. 7) The communication media are called upon to deal with recent scientific advances from an Islamic perspective in a faithful way and avoid employing their services against Islam, aiming to educate the public to be confident before any decision.

2) Cord blood transplantation. Since the first successful use of cord blood as source of hemopoietic stem cells for transplantation in 1988, more than 2000 patients with malignant or non-malignant disorders have been treated with this procedure. Collection and storage of cord blood has prompted ethical considerations, mainly dealing with the issues of autonomy in making decisions about donation of cord blood, and of privacy and confidentiality in the tests required before use of placental cells for transplantation.⁴⁶ Newborn babies are non-voluntary donors of placental blood, and clinicians cannot use this blood without the informed consent of the mother (the father's consent is usually not considered a legal requirement). The need to screen for the infectious and genetic diseases transmissible by transplantation of cord blood can cause problems in terms of privacy, professional confidentiality, and sometimes serious repercussions entailed by information about development of severe congenital diseases for which there is no cure.⁴⁷

The Islamic Jurisprudence Council of the Islamic World League (Organization of Islamic Countries) in Makkah Al-Mukarama in its 17th session (19-23 .10.1424 H/ 13-17 December 2003G) have declared Decree number 3 on stem cell therapy:

First, it is permissible to obtain stem cells, to be grown and used for therapy or for permissible scientific research, if its source is legitimate, as for example 1) adults if they give permission, without inflicting harm on them. 2) Children, provided that their guardians allow it, for a legal benefit and without inflicting harm on the children. 3) The placenta or the umbilical cord, with the parents' permission. 4) A fetus if spontaneously aborted or when aborted for a therapeutic reason permitted by Sharia, with the parents' permission. Be reminded of decree # 7 of the Council in its 12th session about abortion. 5) Left over zygotes remaining from in vitro fertilization, if donated by the parents, when it is ascertained that they will not be used in an illegal pregnancy.

Second, it is forbidden to use stem cells, if their source is illegal. As for example: 1) Intentionally aborted fetuses (that is, abortion without a legal medical reason). 2) Intentional fertilization between a donated ovum and sperm. 3) Therapeutic human cloning.

3) Somatic gene therapy. Somatic gene therapy (SGT) involves introducing an exogenous gene sequence into an organism, to act as a substitute for an endogenous gene that produces inadequate or aberrant protein. Somatic gene therapy currently lies in the uncertain grey area between novel research topic and therapeutic reality. Clinical trials began in the early 1990s, and attempts to provide SGT for a number of conditions notably cancer, acquired immune deficiency syndrome and inherited diseases are underway. The clinical efficacy and safety of SGT, however, remain disputed, and no form of SGT is yet in routine use. In the years of professional discussion of human genetic manipulation, an ethical consensus has evolved. This views SGT as an extension of conventional medical interventions, and identifies the predominant ethical issues associated with SGT as: (i) the anticipated risk/benefit balance, (ii) the selection of appropriate patients, (iii) the provision of information to patients so that informed consent can be given, (iv) the preservation of patient confidentiality, and (v) the cost to the healthcare system.^{48,49}

We (God) created Man in the most perfect form (The Holy Qur'an 95:4).

Often used to explain that each human life has its own inherent value and goodness. Whilst genetic research and gene therapy may have positive uses in serving to restore health (and in the process integrity), care must be taken to ensure that other Islamic principles are not violated. An accurate and complete knowledge of one's pedigree is a fundamental human right; only somatic cell lines should therefore be used in gene therapy since parental integrity is then not compromised and there is no question of hereditary characteristics being influenced.⁴³

In conclusions, genetic testing should be undertaken as part of public health measures to prevent disease, promote health-enhancing behavior and to provide accurate and useful risk perception to a better informed public. Alliances of organizations supporting families affected by genetic disorders and individual groups should be major contributors, along with professionals, to the design of genetic services and development of appropriate measurement and valuation tools. Marked health improvements from integrating genomics into individual and public health care depend on the effective education of health professionals and the public about the interplay of genetic and environmental factors in health and disease. The media are crucial sources of information about genomics and its societal impli-

cations. Initiatives to provide the media with greater understanding of genomics are needed. High-school students will be both the users of genomic information and the genomics researchers of the future. Especially as they educate all sectors of society, high-school educators need information and materials about genomics and its implications for society, to use in their classrooms.⁵⁰ The majority of Asian and African countries population are Muslims by religion. The Arabian peninsula is the cradle of the Arabs, and Islam is their religion since it was established by prophet Mohammed, in 622AD in Madina.⁴³ Islamic teachings offer a great deal in the prevention and control of genetic diseases to Islamic community. It is important to educate to people the danger of consanguinity, which is very common in these countries. Pre-marital examination should be encouraged which may detect the trait in those intending to get married. Proper counseling should be provided, the dangers explained and the options discussed. Prenatal diagnosis and the option of abortion for serious devastating diseases (prior to 120 days from conception) will reduce the incidence of such diseases. Neonatal screening can avert devastation by simple measures namely specific diets. Avoiding teratogens and provision of folate and iodine in the diet will help in reducing congenital diseases. Stem cell and gene therapy are very promising if used within the Islamic context. A minimum level of cultural awareness is a necessary prerequisite for the delivery of care that is culturally sensitive. Once equipped with such understanding it is possible to move beyond the "recipe book" approach to dealing with minority traditions, offering the opportunity for experiential learning. In this paper, we have simplified and highlighted certain key teachings in Islamic medical genetics ethics and explored their applications. We hope that the insights gained will aid clinicians to better understand their Muslim patients and deliver care that pays due respect to their beliefs. Strategic plans need to be put via establishing a strong international leadership by the scientific community, international organizations, governments, and industry, with critical analysis and systems development, actually health system must balance 2 purposes. In the short term they must respond to the demands of the publics for access to existing services. At the same time they must try to improve the health of the whole population. In genetics population screening programs for detection and prevention of genetics disorders and birth defects, with genetics data registry, and systemic follow up of the probands, are of utmost importance.

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