Genetic Counseling in the Muslim World: The Challenges

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Abstract

Genetic counseling is the process in which an individual or a family obtains information and advice about a genetic condition that may affect the individual, his progeny, his relatives, or the family as a whole. Based on this knowledge, he can take the pertinent decision regarding marriage, reproduction, abortion and health management. Genetic counseling includes five themes, medical management, risk determination, risk options, reproductive decision making, and support services. 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. Genetic counseling involves a partnership of physicians, genetic counselors, and genetics support groups. The majority of clinical geneticists subscribe to the principle of non-directiveness: information about risks, natural history, treatment, and outcome are presented in a balanced and neutral manner, but decisions about reproduction are left to the family. In the Muslim World and in the Kingdom of Saudi Arabia (KSA) it involves many challenges, as it has to be carried within the context of religion and culture, according to Islamic ethical and cultural background of the individual, with community-based genetic counseling in one’s own language, in the presence of paucity of expertise, resources and technology. 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 WHO 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”. 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, including premarital screening, pre-implantation genetic diagnosis, newborn screening; assisted reproduction technology; stem cell therapy and genetic counseling.
تحديات الاستشارة الوراثية في العالم الإسلامي

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المناخ

الاستشارة الوراثية هي وسيلة يحصل من خلالها النور أو الأسرة المصاب أو الحاملة لحالة وراثية معينة على معلومات عن هذه الحالة التي قد تؤثر على الفرد وذريته وأقربائه أو على العائلة أجمع. كما تُقدم النصائح اللازمة في هذا المجال. وبناءً على المعلومات المقدمة، قد تكون الاستشارة الوراثية غير ضرورية أو ضرورية للإجابة على أي أسئلة أو الاستفسارات.

تتعلق الاستشارة الوراثية على مناقشة خمس محاور هي: سبل العلاج، وشرح المخاطر المتصلة، وتحديد المخاطر للفرد، وتحديد الخدمات الداعمة. وتتعدد الحلول المشتركة الحكومية لزيادة نسبة المساهمين بالأبحاث الجينية الخاصة في الدول الغير مقدمة حيث غالبية سكانها من المسلمين. لذلك من الضروري أن يتحاصل الفرد على المعلومات المناسبة عن هذا المجال، ويتخذ القرارات التربوية المناسبة لتعزيز الاستخدام الصحيح لهذه التقنيات.

تعد الاستشارة الوراثية مشتركة طبيعية وأخلاقية وتتعدد حالات الاستشارة التي تؤثر على الفرد، وذريته وعائلته. وبناءً على هذه الاحترافية، يمكن أن تُقدم الاستشارة الوراثية على مستوى العالم الإسلامي بشكل عام، وتعتبر الاستشارة الوراثية يعتبر أول استشارة توفر معلومات عن المخاطر المرتبطة بحالات الوراثة، وتوفر الموارد المناسبة ل للغاية هذه الاستشارة.

تتطلب الاستشارة الوراثية توفير المعلومات المناسبة، وتتضمن الاستشارة الوراثية في العالم الإسلامي، تغطي الحالات الشائعة مثل الأورانيوم، والوراثة، والوراثة الجينية، والوراثة المتلازمة، والوراثة النشطة، والوراثة الشقيقة، والوراثة الجينية، واتساع استخدام الخلايا الجذعية، والعلاج بما فيها الأمراض عظيمة للارتقاء بالصحة العالمية. وتقوم الاستشارة الوراثية في المجالات المختلفة، وهي انتخاب النور الصحيح للإجابة على أي أسئلة أو الاستفسارات.

تتزايد ندرة الخبراء وتشكل قضايا الأخلاقية والقانونية والدينية الناجمة عن التكنولوجيا الحيوية. تعقيدًا عندما يكون النور رملاً للرعاية، والعلاج، والوقاية، واتساع استخدام الخلايا الجذعية، والعلاج بما فيها الأمراض عظيمة للارتقاء بالصحة العالمية. وتقوم الاستشارة الوراثية في المجالات المختلفة، وهي انتخاب النور الصحيح للإجابة على أي أسئلة أو الاستفسارات.
Introduction

Islam is the continuum and the culmination of, not an alternative to, the sister Abrahamic faiths of Judaism and Christianity. In the Quran, they are links of the one chain of God's message to humanity. The Quran, which Muslims believe is God's very word, says: **The same religion He enjoined on you as the one He enjoined on Noah, and this We reveal unto you and that We enjoined upon Abraham, Moses and Jesus, that you should uphold the faith and break-not your unity therein (42:13).** This commonality we respect, although we are aware that on further comparison it is natural to find differences and distinct schools of thought between the faiths, and even within one faith.

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. This culture is further refined by various cultures based on their inclinations and sensitivities. Some differences among Muslims are attributable to differences of opinion by various schools of jurisprudence (Risper-Chaim, 1989), of which there are seven major ones: Hanbali, Maleki, Hanefi, Shafe’i, Ja’fari, Zaidi in Yemen, Abadyaha in Oman. Others are not Islamic but ethnic, and may even violate Islamic norms.

Between the 6th and 10th days of Rabi the First, 1401H (January 1981 CE), an international conference on Islamic Medicine was held in Kuwait, to mark the advent of the 15th century of Hejira. One fruitful outcome of this meeting was the Declaration of Kuwait, which deals with the Ethics of medicine in the light of Islamic law (Editorial, World Med J, 1982).

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 three 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 (Weijer et al., 1997).

Islamic bioethics derives 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 Quran and the tradition of the Prophet Mohammad (**Sunna**), and thus to the interpretation of Islamic law. 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 be taken into account (Daar and Khitamy, 2001).

Development of **Sharia** in the Sunni branch of 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; Kamall, 1991).

The four main concerns of Islamic ethics are similar to that of Western ethical systems: autonomy, beneficence, non maleficence, and justice (Van Bommel, 1999). Islamic law (**Sharia**), is in spirit dynamic and flexible, exemplified by the idea that “necessity renders the prohibited permissible” (Paladin, 1998).

Common Indications for Genetics Referrals

- Presence of a possible single-gene disorder.
- Presence of a chromosomal disorder, including balanced rearrangements.
- Person at risk for a genetic condition, including questions of pre-symptomatic diagnosis.
- Person or family with questions about the genetic aspects of any medical condition.
- Evaluation of a person with mental retardation or developmental delay.
- Evaluation of a person with single or multiple malformations; question of a dysmorphic syndrome.
- Evaluation of a person with a possible inherited metabolic disease.
• Couples with a history of recurrent miscarriages.
• Consanguinity in a couple, usually first cousin or closer relationship.
• Teratogen counselling.
• Pre-conceptional counselling and risk factor counselling, including advanced maternal age and other potential indications for prenatal diagnosis.

Impact of Genetic Diseases on the Muslim Population

1. Impact on the patient and the family
   a. General Quality of life
      • Patient suffering.
      • Parents enormous guilt/shame.
      • Burden of care.
      • Psychological distress.
   b. Adverse effects on the family dynamics
      • Focus on sick child, less attention on normal children.
      • Marital stress.
   c. Genetic Stigmatization

2. Impact on health care professionals
   • Medical Care - limited to supportive care.
   • Frustration - untreatable diseases.
   • Genetic counseling (prenatal diagnosis/termination).
   • Desperate therapies (mixed outcome).

3. Impact on the Community and Society
   • Medical/supportive costs.
   • Community need to provide prevention and/or treatment.

Genetics Counseling: the Challenges

Genetic counseling is the process in which an individual or a family obtains information and advice about a genetic condition that may affect the individual, his progeny, his relatives, or the family as a whole. Based on this knowledge he can take the pertinent decision regarding marriage, reproduction, abortion, and health management.

A review of the combined files of the Riyadh Military Hospital, Riyadh, over 10 years period, documented more than 150 varieties of neurodegenerative disease among 2,000 children. Some autosomal recessive disorders are common (e.g., sickle cell anemia). Others are unique (e.g., Al Aqeel Sewairi syndrome). In these disorders, the exact molecular defect is found. Therefore, prevention is possible by either pre-implantation genetic diagnosis or prenatal diagnosis in accordance to the recommendation of Islamic scholars.

These diseases are clinically recognizable through certain symptoms and signs. Their early recognition is important to initiate treatment and to prevent neurologic crippling. Counseling families in the Muslim world must be done in accordance to the cultural and religious guidelines, to initiate treatment and to prevent these disorders. Counseling will include other family members since the impact of these disorders include other family members with recurrence risk. However, as treatment is either difficult or expensive or unavailable in some centers, therefore, prevention is of utmost importance.

On counseling patients and families with genetics disorders, many challenges are encountered:

• Dealing with patients with complex disorders, like diabetes, hypertension, and obesity, is associated with difficulties in mapping genes and finding the exact genetic defect. However, dealing with patients with single gene disorders, in the presence of high degree of consanguinity, which ranges between 30 - 70% in our Muslim population, with several affected members in these families gives a unique opportunity of mapping genes (e.g., Al-Aqeel Sewairi syndrome).
• The specific culture and religion.
• Availability of technology and resources including human resources.
• Availability of data registries, including mutation registries.
• Establishing a mechanism of collaboration, whether at national, regional or international levels. In this regard, CAGS is an important example of regional collaboration in the Arab World.
• Availability of preventive measures.
• Availability of expertise.
• Availability of supportive services.
• Public education.

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 (Pang, 2002).

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 (Luri and Wolfe, 1994). This is one of the concerns of the World Health Organization, 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 (Report of the Advisory Committee on Health Research, 2002).

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 because of three 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 (Burgess et al., 1998).

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 (Etchells et al., 1996). 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 (Daar and Al-Khitamy, 2001). 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 Hanball School of jurisprudence is 15 years while Abu Hanifa and Malek 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).

In Islamic countries, genomics research needs to be regulated within the context of culture and religion. The Islamic Jurisprudence Council of the Islamic World League in Makkah Al-Mukarama regularly hold conferences in situations requiring specialist knowledge (for example, decisions concerning medical practice, or research). Hence, 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), 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 two 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 (Kamali, 1991; Van Bommel, 1999; Daar and Al-Khitamy, 2001).

The Islamic Organization for Medical Sciences, based in Kuwait, also holds conferences and publishes the Bulletin of Islamic Medicine (www.islamset.com). Most Islamic communities, however, would defer to the opinion of their own recognized religious scholars (Daar and Al-Khitamy, 2001).
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 (Albar, 1999).

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, 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 in the Holy Quran: There should be no compulsion in religion (2:256). A counselor should seek to provide accurate, sincere advice, but should not try to impose it upon the client (Albar, 1999).

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 (El-Hashemite, 1997; Bernadette and Aamra, 2002). 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 (Bernadette and Aamra, 2002). Moreover, Islamic teaching discourages first-cousin marriages (Albar, 1999).

In 1994 and 1996, the World Health Organization’s Regional Office for the Eastern Mediterranean (which covers North Africa and the Middle East, including Pakistan) convened two 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 (Bernadette and Aamra, 2002).

Genomic Research and Islam

Genomics provide 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 (Collins et al., 2003).

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 (11 Rajab H /31 October 1998 CE), which decided the following:

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 Shari'a.
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 H /5 - 10 January 2002 CE) 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); (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 Shari'a.
2. DNA fingerprinting may be used in lineage (genealogy) only with great caution and confidentiality as the Shari'a 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 fingerprint 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:
   • 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).
   • In cases of disputes over babies in hospitals and nurseries or test-tube babies.
   • In cases of children lost because of war, accidents or natural disasters, where their family could not be found.
   • 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 (Donnai, 2002).

A statement from a WHO expert consultation 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’ (WHO, 2000).

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 (WHO, 1997).

Primary Prevention Strategies

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; e.g., alcohol, smoking) should be avoided as the prophet Mohammed, said: “Do no harm” (Albar, 2002).

Pre-marital or Pre-pregnancy Genetic Screening: Genetic blood disorders (thalessemia 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 thalassaemia 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 (WHO, 1999).

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. These involve 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 (Weatherall, 1998).

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 2003 CE) having looked into the legitimacy of pre-marital medical screening of Genetic Blood Disorders, and has decided:

1. 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.

2. 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 done 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 like 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 (Martignetti et al., 2001; Al-Aqeel et al., 2003).

**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 (Ozand et al., 1992). 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 (El-Hazmi and Warsy, 1996).

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 1 in 5000 live births (Rashed et al., 1997). 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 (Scriver, 1996). 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 prenatal diagnosis, pre-implantation diagnosis, and sperm or egg donation, the avoidance of further pregnancy, or adoption.

**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 two or three 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 (Albar, 1999; Hussain, 2003).
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 Quran says: **God did not make your adopted ones your sons** (33:4). (Albar, 1999; Albar, 2002; Hussain, 2003).

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 (Albar, 1999; Albar, 2002; Hussain, 2003).

A November 2000 workshop organized by the International Islamic Center for Population Studies and Research, Al-Azhar University, Cairo, considered use of assisted reproduction technologies (ART) in the Islamic world. The same above conclusions were drawn, including no embryo transplantation after husband death (Seroura et al., 2001).

Pre-implantation diagnosis: Pre-implantation genetic diagnosis (PGD) was introduced at the beginning of the 1990s as an alternative to pre-natal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a sex-linked genetic disease (Sermon and Van Steirteghem, 2004). Pre-implantation genetic diagnosis (PGD) is an early form of pre-natal diagnosis, where in vitro fertilization is carried out. Zygotes are grown to 8-cell stage (morulla 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 two broad indication groups. The first group are individuals at high risk of having a child with a genetic disease (e.g., 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 (Sermon and Van Steirteghem, 2004).

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 sex-selection or family balancing, considering that each case should be treated on its own merits. Sex selection technologies have been condemned on the ground that their application is to discriminate against female embryos and fetuses (Seroura et al., 2001).

Ethically Difficult Indications

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 (Stern et al., 2002).

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 (Pennings et al., 2002). 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 (Verlinsky et al., 2002; Robertson, 2003). Finally, several reports have been published on the use of sexing for social reasons and have provoked mixed reactions (Ray et al., 2003).

In Saudi Arabia, PGD is carried out for carriers of a monogenic diseases or of chromosomal structural aberrations, such as translocations, with good results (Hellani et al., 2004).

Prenatal 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 (Strong, 2003).
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 (Albar, 2002).

Each of you will have had his created existence brought together in his mother’s womb, as a drop (nutfa) for forty days, then a leech like clot (alaqa) for the same period, then a piece of flesh (mudgha) for the same period, after which God sends the angel to blow the spirit (ruh) into him (Seroura et al., 2001).

The fatwa #4 of the Islamic Jurisprudence Council of the World Islamic League (Organization of Islamic Countries) at its 12th session (15 - 22 Rajab 1410H/10 - 17 February, 1990 CE) 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.

Cloning and stem cell research: Cloning is the production of two 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 (Wakayama, 2004).

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 (Tauer, 2004).

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 (Tauer, 2004).

In late 2003, two 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 (Tauer, 2004).

The Islamic Jurisprudence Council of the Organization of Islamic countries) in Jeddah in its 10th session (23 - 28, 21418H / 28 June - 3 July 1997 CE) explored all the research papers and recommendations of the 9th Medical & Fiqh Seminar held by the Islamic Medical Organization in Casablanca, Morocco, in collaboration with the Council and others (14 - 17 June 1997 CE), and declared Decree #100/ 2/D10.

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.

**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 (Burgio et al., 2003).

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 (Burgio et al., 2003).

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 2003 CE) have declared Decree #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.

**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. SGT 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 (Scully and Rehmann-Sutter, 2001; Scully et al., 2004).

We (God) created Man in the most perfect form (The Holy Quran 95:4); this verse is 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 (Gatrad and Sheikh, 1999).
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 implications. 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 (Collins et al., 2003).

The majority of Asian and African populations 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 622 CE in Madina (Gatrad and Sheikh, 1999). 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. Pre-natal 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 two 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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References

and support should be given to women, especially those who are carriers. Women readily accept the responsibility for the health of their future family and therefore women must be fully informed about possible prevention along with their husbands, so that decisions about any future methods of prevention are shared. It is necessary that clear explanations be given about possibility of predictive genetic tests.

Reassurance for carriers is important. The explanation should be given that to be a carrier is not an illness and not a God’s punishment. Being a carrier is not shameful and is often associated with advantage for survival. In the case of sickle cell disease, carrier is selected by nature for survival against malaria. A carrier will not develop illness later on. The advantage of knowing one is a carrier is to be able to plan a healthy family and avoid genetic disease.

Health Education: Using Genetic Knowledge for Prevention

Educational efforts may wish to increase understanding by communities that genes can have deleterious effects and cause diseases throughout the life span. Above all, people throughout society must be helped to understand that everyone carries a number of “variant” genes, which may induce severe illness in our children, or may show effect in later life. It is important to stress that a child with genetic disease is not a punishment from God; the gene for a recessive disease is inherited from both parents but parents are not responsible for the combination of genes they have and can not be blamed.

New methods of health education should be developed and promoted. A new genetic Arabic vocabulary may need to be established, which is less damaging to patients and their families. In particular, much understanding of the impact of specific words in the Arabic language is required.

A paradigm shift in medical education is needed, one with more emphasis on training future physicians to enhance their empathy skills and to learn to view patients as persons, not just cases.

Sensitive Approaches

Families with handicapped children should not be blamed, criticized, judged or ridiculed, but should be supported in all ways possible. Health practitioners need to adopt a sensitive approach in providing health information paying attention to their vocabulary to ensure that unintended meanings are not communicated. The management of those affected with genetic diseases goes well beyond a short period of an acute episode of illness. Psychological rehabilitation for the affected and his relatives can be equally important as acute treatments, and often, even more important.

Every effort should be made to minimize diagnostic uncertainty (WHO, 2004; Condit et al., 2004). The value of genetic diagnosis encompasses (beyond clear plan of treatment) family planning, recurrence risk for siblings, and a significant emotional relief for the parents. Each family has the right to an explanation for a handicap, to appropriate investigation and to information as to how molecular diagnosis may open the way to prevention (Al-Odaib et al., 2003; El-Hazmi, 2004a). Parents need to be educated about how genetic disease recurrence could be prevented, and how relatives can also avoid the same condition.

Special consideration must be given to preserving the privacy and integrity of families living in rural communities. Unintended “advertisement” of their genetic disadvantage may result if professionals visit and pay attention excessively to families with genetic disease with offers of counselling, premarital tests or research (El-Hazmi, 2004b).

It would is essential to discuss with parents of newly diagnosed children with genetic disorders how they wish to maintain confidentiality as well as what support services they need. Families need assistance to develop coping strategies with follow-up.

Integrated Management

An integrated approach to the management of the children with disadvantages, requiring support from primary health care institutions, social agencies and community support groups, is an essential adjunct to genetic counseling services. The community support groups and associations are able to play a major role in helping parents to manage disabled children in terms of sharing practical experience with other parents about therapies and increasing relevant skills, and with respect to emotional aspects such
as getting a sense of belonging to a community.

Only if it is accompanied by visible commitment to the care of affected people will a prevention programme be credible and able to gain the confidence and co-operation of affected families (Rajab and El-Hazmi, 2007).

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