

IV Islamic Bioethics in the Context of Medical Genetics

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نبذة مختصرة

يشكل ارتفاع معدلات المواليد المصابين بالاضطرابات الوراثية عبئاً كبيراً على نظام الصحة في المملكة العربية السعودية، تؤثر هذه الاضطرابات سلباً على نوعية حياة الفرد المصاب وأسرته. كما أن لها أثراً على المجتمع السعودي ككل. تساهم مختلف أساليب الوقاية والعلاج في التخفيف من عبء الاضطرابات الوراثية بشكل فعال على الفرد والمجتمع. ولكن تواجه هذه الأساليب العديد من التحديات، بحيث أن في المملكة العربية السعودية وكذلك في دول إسلامية أخرى: يجب أن يتم تنفيذ هذه الأساليب بلغة الفرد المصاب، ووفقاً للأصول المنصوصة من الدين الإسلامي أولاً، والعادات والتقاليد الخاصة بالمجتمع السعودي ثانياً. علاوةً على ذلك، فالخبرات والموارد اللازمة للوقاية من الاضطرابات الوراثية وعلاجها لا تزال محدودة في المملكة. في هذا الفصل، نناقش بعض هذه التحديات بالتفصيل، ونراجع التعاليم الإسلامية المرتبطة بأساليب الوقاية والعلاج المستخدمة في المملكة العربية السعودية.

Abstract

The Saudi population and its healthcare system are burdened by high rates of births with genetic disorders, which greatly impact the patient's quality of life as well as that of their family. Such disorders also affect the patient's community and society as a whole. Prevention and management methods play a big role in reducing this burden. In the Muslim World and in the Kingdom of Saudi Arabia (KSA), such methods face many challenges, as they have to be carried within the context of religion and culture, according to Islamic ethical and cultural background of the individual, in one's own language, as well as in the presence of limited expertise, resources and technology. Here we discuss in detail the challenges faced and the relevant Islamic teachings that govern the prevention and management of genetic disorders.

Introduction

Public health authorities are increasingly concerned by the high rates of births with genetic disorders. Genetic diseases have a great impact on people worldwide and on muslim populations. They affect the patient's quality of life as well as that of the family, causing suffering and psychological distress on both. This often, in turn, leads to adverse effects on family dynamics. For example, the parents become focused on the patient, which leaves less attention for other siblings. Genetic diseases also constitute a burden for healthcare professionals, as well as the patient's community and society as a whole. Prevention and management methods play a big role in reducing this burden.

Genetic counseling is the process by which an individual or a family obtains information and advice about genetic condition(s) that may affect the individual, their progeny, their relatives, or the family as a whole. Based on this knowledge, he/she can take pertinent decisions regarding

marriage, reproduction, abortion, and/or health management (1).

Counseling includes five themes: namely, medical management, risk determination, risk options, reproductive decision making, and support services. It 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. However, decisions about reproduction are left to the family, making the role of genetic counselors very essential (1).

We are at a time of unprecedented increase in genomics and genetics knowledge. Along with such advancements, ethical, legal, social and religious issues are raised. 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 & preventive measures, including genetic counseling and population genetic screening.

Bioethics in Islam

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 Muhammad (*Sunna*), and thus to the interpretation of Islamic law (*Sharia*). 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 (1, 2).

Islamic law is in spirit dynamic and flexible, exemplified by the idea that “necessity renders the prohibited permissible” (3, 4). Islam thus also has the flexibility to respond to new biomedical advancements. Many aspects of medicine and scientific research, including genetics/genomics research, biotechnology, stem cell research, as well as tissue and organ transplantation, are carefully evaluated and regulated by Islamic bioethics. For instance, the benefits of molecular genetics and bioengineering 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 Rajab 1419H /31st October 1998G), whose main decision was to allow the use of genetic engineering for disease prevention, treatment, or amelioration on the condition that such use does not cause further damage (1).

Genetic Counseling: the Challenges

Genetic counseling requires a comprehensive knowledge of genetics, disease management, and disease impact on the individual, the family, offspring and the community at large. In the Muslim World and in the Kingdom of Saudi Arabia (KSA), counseling involves many challenges, including the lack of availability of data registries (including mutation registries); the scarcity of preventive measures, expertise, and supportive services; the lack of public awareness about genetics; as well the widespread norm of consanguineous marriages (see below). In addition, counseling has to be carried out according to Islamic ethical and cultural background of the individual (1, 3).

Islamic teaching encourages counseling. The Prophet Muhammad said: “Religion (Islam) is sincere counseling and good advice”. The Prophet Muhammad also said: “The counselor should be trustworthy”. Indeed a counselor should be considerate and compassionate, and should maintain absolute confidentiality of the person(s) or family involved. Giving good advice to those who need and ask for it is the basis of Islamic ethics in general, and of medical ethics in particular (beneficence). A counselor should seek to provide accurate, sincere advice, but should not try to impose it upon the client (5). The counselor must also provide genetic information in plain, understandable language, while taking into consideration the clients’ social and cultural habits.

Consanguinity in the Kingdom of Saudi Arabia

A consanguineous marriage is defined as marriage between people who are second cousins or closer, but leads to and increases birth prevalence of infants with severe recessive disorders (6, 7). It is customary among Middle Eastern populations, Irish travelers, Zoroastrians, some Jewish communities, and many tribes in sub-Saharan Africa and South East Asia. Although the custom is often perceived to be associated with Islam, it is in fact independent of religion. It is estimated that 20% of the human population lives in communities with preference for consanguineous marriage, and at least 8.5% of children have consanguineous parents (7). Islamic teaching discourages first-cousin marriages; the second caliph observed weakened progeny in the tribe of Bani Alsa’a’b, due to cousin intermarriage, and advised to “Marry from faraway tribes; otherwise you will be weak and unhealthy” (3).

Approximately 33.6% of all marriages in Saudi Arabia occur between first cousins, another 22.4% constitute other forms of consanguineous marriages, with an overall consanguinity rate of 56%; the rate of consanguinity is higher in rural (59.5%) compared to urban (54.7%) settlements, and specific regions were found to exhibit much higher rates (66-67%) of consanguinity (8). There is an estimated 1.7-2.8% increased risk of congenital and genetic diseases to offspring of first cousin couples (9).

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 aims of such programs are the detection or prevention of genetic disorders and birth defects at the population level (10). Such screening programs can be premarital, pre-implantation, pre-natal, or neonatal. Here we discuss some of these programs and how Islamic teachings regulate them.

Pre-marital genetic screening

Pre-marital screening has been important globally, especially for reducing the prevalence of genetic blood disorders (thalassaemia and sickle cell disease) and Tay-Sachs disease. National screening programs, in various countries around the world, have significantly reduced birth rates of children with such disorders.

In the Islamic population, such autosomal recessive disorders are quite common. For instance, the frequency of G6PD deficiency in the Saudi population is approximately 13%, and was found to be highest in the eastern (37.9%) and western (31.2%) provinces (11). Sickle cell disease and thalassaemia affect between 1-20% of the Saudi population and result in approximately 2,000 affected newborns per year in Saudi Arabia (12).

The Islamic Jurisprudence Council of the Islamic World League in Makkah Al-Mukarama in its 17th session (19-23.10.1424H / 13-17 December 2003G) looked into the legitimacy of pre-marital medical screening of genetic blood disorders, and decided:

- A. 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*.
- B. The Council recommends that governments and Islamic institutions spread understanding on 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.

Multiple Arab countries, including Saudi Arabia, now have a mandatory premarital screening for

sickle cell disease, thalassaemia, and G6PD (13); carrier couples are counseled and advised against marriage but the final decision remains theirs (14). There are currently around 125 centers across various regions in Saudi Arabia which offer premarital screening and counseling services (13). Counseling of at-risk couples resulted in a 5-fold increase of voluntary marriage cancellations and a 60% decrease in the prevalence of β -thalassaemia (13, 15).

Prevention Based on Reproductive Options

Reproductive options 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.

- A. 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 (1). 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 (5, 16).
- B. 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). (5, 16, 17).
- C. Donation of a sperm, ovum or pre-embryo, or motherhood surrogacy: Artificial insemination by a donor sperm, or egg donation, is not allowed 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 is allowed, including surrogacy and embryo transplantation after husband's death (1, 5, 16-18).
- D. Pre-implantation diagnosis: Pre-implantation genetic diagnosis (PGD) was introduced at the beginning of the 1990s as an alternative to prenatal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a sex-linked genetic disease (19). In PGD, zygotes are grown to

8-cell stage (morulla stage) *in vitro*, and then embryos 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 (19). The workshop organized by the International Islamic Center for Population Studies and Research, Al-Azhar University in 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 (1, 18, 20). In Saudi Arabia, PGD is carried out for carriers of monogenic diseases or of chromosomal structural aberrations, such as translocations, with good results (3, 20, 21).

Prenatal Diagnosis

Prenatal diagnosis can detect certain fetal chromosomal abnormalities during early stages of pregnancy. A number of ethical considerations arise with regard to screening for, detecting, and managing fetal anomalies, as based on the results, the parents face the possibility of having to make abortion decisions or management decisions after viability (22).

According to Islamic teachings, human life begins at the time of ensoulment, which is stated in the Hadith (Sayings of the prophet Muhammad, 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 (17).

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 (18).

The *fatwa* # 4 of the Islamic Jurisprudence Council of the World Islamic League at its 12th session (15-22 Rajab 1410H/10-17 February, 1990G) 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 hospitals in Saudi Arabia (1).

Neonatal or Newborn Screening programs

The aim of such screening programs is the early diagnosis of genetic disorders, which may allow the prevention or reduction of their effects. Such programs cover metabolic, endocrine, pulmonary, and blood disorders. For instance, the incidence of inborn errors of metabolism (IEMs) was found to be as high as 1:1043 in Saudi Arabia (23). 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. Early diagnosis for some of these disorders has proven very effective in early treatment or management (24, 25)

Conclusions

Islamic teachings offer a great deal in the prevention and control of genetic diseases to Islamic community. These teachings highlight the importance of educating people about the possible genetic consequences of consanguinity, of encouraging population screening programs, and of seeking counseling. Proper counseling, reduced consanguinity rates, as well as screening programs will continue to reduce the incidence of genetic disorders and their burden on the family, community, and healthcare system.

In this chapter, we have simplified and highlighted certain key teachings in Islamic medical genetics and 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.

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