

# Counselling about genetic disease: an Islamic perspective

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**SUMMARY** Genetic counselling is the process by which an individual or a family obtains information about a genetic condition that may affect them, so that they can take the appropriate decisions about marriage, reproduction and health management. Islamic teaching encourages counselling and stresses that the counsellor should be considerate, compassionate and should keep the secrets of the person or family involved. He/she should not impose his/her views on the clients. Some Arab countries encourage premarital medical examination to detect carriers of common hereditary diseases such as thalassaemia. However, this is still controversial, as it infringes the human rights of individuals. Reproductive options open to carriers of hereditary diseases are outlined in this paper, such as prenatal diagnosis, adoption, donation of a sperm, ova or pre-embryo and preimplantation diagnosis, and their acceptability within Islam is discussed.

## Introduction

Genetic counselling is the process of an individual or a family obtaining information and advice about a genetic condition (that may affect the individual, the individual's progeny, other relatives or the family as a whole), which they can then use to take appropriate, informed decisions about marriage, reproduction, abortion and health management.

## Islam and counselling

Islamic teaching encourages counselling. The Prophet Mohammed (ﷺ) said: "Religion (Islam) is sincere counselling and good advice" (narrated by Al-Bukhari and Muslim). The Prophet Mohammed (ﷺ) also said: "The counsellor should be trustwor-

thy". Indeed a counsellor cannot be trustworthy unless he or she is proficient in the field in which they are giving advice. Genetic counselling is a new field of medicine demanding a comprehensive knowledge of genetics and the management of genetic disease, as well as its impact on the individual, the family, offspring and the community at large. Counsellors should be knowledgeable in their field otherwise they are deemed to be liable. The Prophet Mohammed (ﷺ) said: "If a person practices medicine without due knowledge, then that person is liable" (narrated by Abu Dawood).

Islamic jurists have explained that one should be proficient in the particular field of medicine one practises. It is not sufficient to know only general medicine if one is practising in a special field of medicine. Training in and knowledge of the special-

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ized field is required. The Prophet Mohammed (ﷺ) said: "No one is wise except through experience" (narrated by Al-Bukhari and Muslim).

Being proficient and knowledgeable in one's field is not enough. The counsellor should be considerate and compassionate, and should maintain absolute confidentiality of the person(s) or family involved. The Prophet Mohammed (ﷺ) said: "Whoever guards the secrets of a Muslim, God will guard their secret in this life and on resurrection day" (narrated by Muslim). He (ﷺ) also said: "God will show mercy to those who are merciful to people" (narrated by Al-Bukhari, Al-Tirmithi, Ahmad and others). In another hadith, the Prophet Mohammed (ﷺ) said: "All creatures are the family (dependents) of God. He loves most those who do good to his dependents" [narrated by Al-Tabarani, Abu Naeem (in Al-Hirliya), Al-Baihaqi].

Being considerate, kind and merciful, and 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). The worst thing of all is doing harm intentionally or unintentionally, the first being a crime, the second an offence. The rule of non-malevolence is exemplified by the hadith: "Do no harm" (narrated by Abu-Dawood).

Genetic counsellors should not impose their views on clients. Rather, clients should be able to decide for themselves what is appropriate. The counsellor's role is to provide facts on genetic information in plain, understandable language (the rule of autonomy). The counsellor 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), and also says: *Are you going to compel the people to be faithful? (10:99) Whoever wishes to believe can do so. and whoever wishes to disbelieve is free to do so. (18:29)* The Islamic creed holds high personal freedom and hence the personal responsibility for one's actions. Similarly, genetic counsellors should seek to provide the most up-to-date information in plain, comprehensible language for their clients, and let the clients decide for themselves. A counsellor should seek to provide accurate, sincere advice, but should not try to impose it upon the client.

## Genetic disease and consanguinity in Arabic-speaking countries

Monogenic diseases (diseases inherited through one gene) constitute only a small percentage of the total congenital diseases and malformations (10%–15%), but a much larger percentage of childhood disease. In many Western countries, 50% of all deaths of children up to the age of 15 years are attributed to hereditary disease.

Many of the world's most common diseases have a hereditary component, e.g. diabetes mellitus, hypertension, ischaemic heart disease and cancer. Many neurological and psychiatric diseases are either monogenic hereditary diseases, or else a hereditary factor plays a major role in their causation. Similarly, blood diseases are either caused by a monogenic hereditary factor, or hereditary factors play an important role in their causation.

Thalassaemia and sickle-cell anaemia are examples of autosomal recessive diseases causing illness and great morbidity in many countries, including those of the Mediterranean and the Arabic-speaking worlds. As consanguineous marriage is

common in most Arabic-speaking countries, the incidence of such diseases is high (5%–10% of Arabs carry the thalassaemia gene). Islamic teaching discourages first-cousin marriages. It is narrated that Omer Ibn Al-Khatab, the second khalifa, noticed that the progeny of the tribe of Bani Assayib had become weak and unhealthy because of intermarriage of cousins. He advised the tribe to avoid close-cousin intermarriage and to seek wives and husbands from tribes further afield, saying: "Marry from far away tribes, otherwise you will be weak and unhealthy."

### Premarital testing

Since the first half of the 20th century, many governments in the Arabic-speaking world (Egypt, Syrian Arab Republic, Lebanon, Tunisia and Morocco, for example) have been promoting premarital medical examinations. However, this has had little effect on hereditary disease and consanguinity, there being no means of detecting genetic disease carriers. Moreover, a medical certificate has often been provided without the medical check-up being carried out.

Recently, symposia have been held to discuss the implementation of a law making it mandatory to test for the thalassaemia gene as a prerequisite to obtaining a marriage licence. Still, difficulties abound. The test is expensive and results in major ethical dilemmas. Who will bear the cost of the test? Most governments have more urgent medical priorities for their limited resources. Limited resources or poverty may also put the test beyond the means of private citizens. A mandatory test encroaches on the individual's autonomy. If it is imposed by law, a medical certificate can still be forged

or obtained by other fraudulent means. If a test does prove positive for prospective partners, who has the power to prevent them from legally marrying? To do so would be an encroachment on the autonomy and the human rights of the individual. It would be completely unethical.

### Alternatives to marriage prohibition

Couples whose tests do prove positive, could be counselled to choose a number of alternatives, should they still wish to marry. Such alternatives might include:

- avoidance of pregnancy by contraception or sterilization;
- adoption;
- donation of a sperm, ovum or pre-embryo, or motherhood surrogacy;
- preimplantation diagnosis;
- diagnosis during pregnancy, for example, chorionic villus sampling (CVS), and amniocentesis, blood testing (carried out on both the expectant mother and fetus) and ultrasonography.

### 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.

Most couples yearn for procreation and will not choose sterilization unless there is a serious impediment. Sterile couples often expend extremely large amounts of money, time and energy for the opportunity to have a child. It is impractical to expect couples carrying a recessive gene, as for example the thalassaemia gene, to opt for steriliza-

tion. All of us carry some recessive genes; few would choose celibacy or sterilization for that reason alone. 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.

### Adoption

Adoption was abrogated by the Holy Quran, and Islam does not recognize it as parenthood. The lineage of the child should be to its natural parents, from legitimate pregnancy, as Islam allows procreation only within wedlock. The Holy Quran says: *God did not make your adopted ones your sons. That is only a saying from your mouths, which has no reality. Call them by (the names of their (true) fathers. That is just in the sight of God. But if they know not their fathers, call them your brothers in faith or your wards. There is no blame on you when you are mistaken. What counts is the intention of your hearts. And God is oft forgiving and most merciful.* (33:4,5).

The bringing up of orphans is a great act of charity encouraged by Islamic teaching. The lineage of the child should, however, remain to his true father. Thus, while a couple who is carrying a lethal gene, or a gene that can cause great illness or morbidity to the offspring may not adopt a child, they can care for one or many orphaned children or children of unknown parents. Nevertheless, they will not be true physical parents of the child(ren).

### Donation of a sperm, ovum or pre-embryo, or motherhood surrogacy

Through developments in procreation technology, semen banks and *in vitro* fertilization projects, infertile couples in the West

(or one partner) can get a donated sperm, a donated ovum, a donated pre-embryo (blastula or morula), or make use of the uterus of a surrogate mother. Islamic teaching limits procreation to within wedlock, and hence between husband and wife only. There should be no third party in the process of procreation, i.e. no donated sperm, ova or pre-embryo, and no surrogacy. Muslim couples carrying a lethal gene or one likely to cause serious disease may not use any of these technologies. All are refuted by Islamic jurists, who insist that the act of procreation be limited to spouses alone, without the intervention of third parties.

### Preimplantation diagnosis

Due to technological advances in the last decade of the 20th century, it is now medically possible to remove one or more cells from the blastula (a pre-embryo) prior to its implantation in the uterus. Fertilization occurs *in vitro*, by taking the husband's semen and allowing it to fertilize the ovum of the wife, like any *in vitro* fertilization project. When fertilization occurs, the zygote is allowed to grow to the blastula or morula stage (a few days after fertilization). If there is a possibility of genetic disease or chromosomal abnormality (e.g. trisomy 13, 18 or 21), one or more cells are taken from the blastula and examined for the suspected defect. If the blastula is shown to bear the defective gene or chromosome, it is discarded and another tested. Only blastulae free from genetic or chromosomal defects are reimplanted.

A disadvantage of this technology is the low reimplantation success rate. Best practice achieved to date has so far produced a pregnancy success rate of 30%, with successful births numbering approximately 15% of total attempts. The advantage of the method is that it avoids abortion.

This technology is also a probable precursor to gene therapy and gene alteration at an early stage in the human life cycle, which although not yet being carried out, will surely come in the near future. However, there are fundamental ethical problems regarding gene therapy in germ line and germ cells that will need to be addressed, along with the technical problems of gene therapy.

### Diagnosis during pregnancy

Diagnosis of congenital malformation, genetic disease and chromosomal abnormality are becoming possible with new developments in medicine.

Simple blood tests carried out on the expectant mother may help in diagnosis (e.g. increased  $\alpha$ -fetoprotein in cases of neural tube defects, namely anencephaly and spina bifida). Ultrasound can detect many dysmorphic abnormalities and assists in the diagnosis of congenital defects of the heart, brain and kidneys.

CVS can be carried out during the 8th week of pregnancy to detect suspected genetic and chromosomal defects. Similarly, amniocentesis can diagnose such defects, but at a later stage of pregnancy (14–16 weeks). The advantage of early diagnosis in CVS is offset by a higher percentage of abortion and complications (2%–3%) compared with amniocentesis, which is much safer but gives a late diagnosis. The couple is given the choice of abortion when a serious congenital or hereditary condition is discovered.

### Islam and abortion

The fatwa of the Islamic Jurisprudence Council of the World Islamic League at its 12th session (10–17 February, 1990) in

Mecca, 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.

Many dilemmas remain. Is it allowable to abort a Down syndrome fetus, which if carried to term and given birth, could likely live a quiet, peaceful and love-giving life? Is it acceptable to abort if the Huntington disease gene is detected — the disease is unlikely to appear until the person is 40 years, or even 60 years old? Is it permissible to abort those who are homozygous for sickle-cell disease or thalassaemia, or phenylketonuria or homocystinuria; the latter two diseases can be cured simply by avoiding foods containing phenylalanine or methionine? Similarly, treatment exists for the haemolytic anaemias by way of blood transfusion and iron chelation therapy.

The near future may well have in place gene therapy for such diseases, negating the need for abortion. For now, the best policy is to encourage couples planning marriage to undergo premarital examination for infectious and hereditary diseases common in their communities. Equally important is the discouragement of close-relation consanguinity, at present still common in many Arabic-speaking countries.