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Genethical Aspects of Research and Medical Services in Islamic Countries

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1. Introduction

Islam has approximately 1.5 billion followers worldwide, the majority of whom live in Arabic/Islamic states with an appreciable number live in non-Islamic states.^{1,2} In both environments the Muslims maintain a "Code of life", where they adhere to the instructions of Islam and respect its guidance in all aspects of their daily life. In this respect, Islam responds to person's need through the "Code of Conduct" drawn from Al-Sharea'h, the Islamic law.^{3,4,5,6,7,8} The Teaching of Islamic Law include all that is required to appropriately serve the needs of the individual, the family and the community at large.³

To respond to various issues learned from Human Genome and associated studies, varieties of scientific activities, including conferences, symposia and workshops were held during the last 15 years in a number of Islamic countries to discuss the new issues arising from the scientific and technical developments and their applications in genetical practices. These include an international conference on Islamic medicine held, to discuss ethics of medicine in the light of Islamic views and a seminar on "Genetics, Genetic Engineering, the Human Genes, and Genetic Treatment - An Islamic Perspective".⁹ Thereafter, World Health Organization (W.H.O) organized two relevant meetings. A meeting to discuss "Ethical aspects of scientific application in Genetics", followed by another meeting to discuss the "Ethical issues in application to genetics in developing countries", which include a large number of Islamic countries.^{10,11} A complementary workshop entitled: "The 1st Regional workshop on Ethical issues in Genetic counseling" was held, thereafter.¹² The last three events benefited from the previously held conferences and from related "Fiqh" Council Fatwas, the guidelines of the Learned. Of significance also, is the United Nations Educational, Scientific and Cultural Organization (UNESCO) general guidelines on Bioethics and Human rights.¹³

2. Genetic investigations and community ethical beliefs

As Science has global identity, research was advanced by collaborative efforts between scientists from various countries. However, the genetic research outcome encroaches into the individuals and the family beliefs in all communities. Nevertheless, the basic ethical aspects remain universal, though with specific unique features that are relevant to the concerned community, its societal beliefs, customs and prevailing traditions.

In general, Medical Ethics combines a set of societal values and beliefs that are relevant to diagnosing illnesses, preventing and controlling diseases and provision of care for patients.

The health care teams are required to conduct research and acquire further knowledge and technology to help improving medical care. The balance between the medical services and research aimed to enrich knowledge, is necessary, but has to meet a battery of ethical elements, including:^{6,14 -18}

- Autonomy
- Beneficence
- Non-maleficence
- Justice
- Confidentiality
- Medical professionalism

In Islam, the Holy Book of Moslems (The Qur'an) and the Prophet's instructions (The Hadeeth), Peace Be Upon Him (PBUH), the Consensus (Al Ijmaa') of the Learned (Al-Ulama) and Analogy (Al Qiyas) on the newly found matters of life, are the sources of religious practices and govern all aspects of life through Al-Sharea'h.¹⁹⁻²⁴ Consideration is also given to "Maslaha" (public interest) and urf (the local customary precedent).²¹ These Islamic teachings are in line with the ethical elements observed in medical practices (Figure 1).

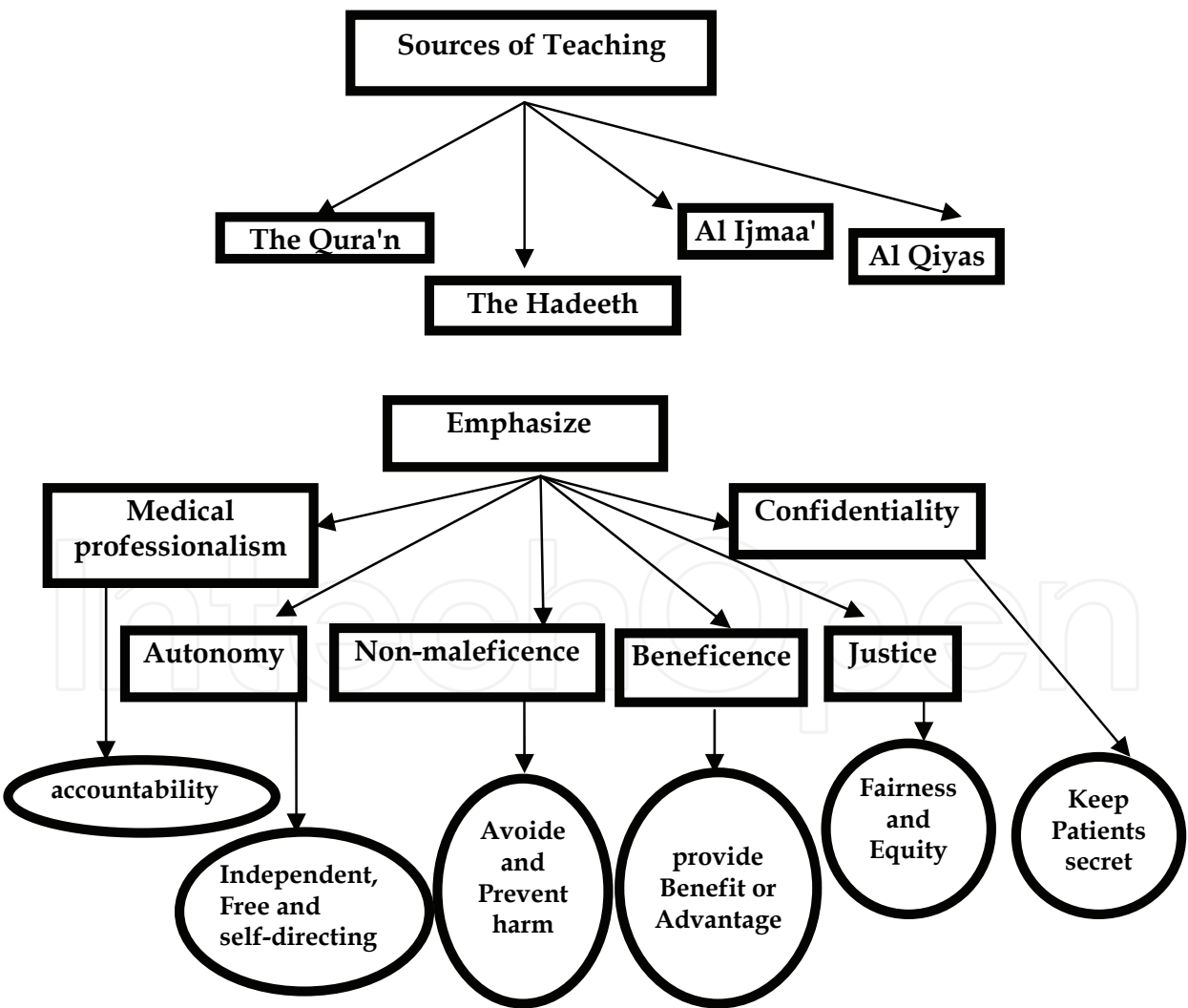


Fig. 1. Features of Islamic Teachings

The Arabian Peninsula is the cradle of Arabs and Islam, with the two Holy Mosques of Moslems in the cities of "Makkah Al Mokarramah" and "Al-Madinah Al-Monawarrah" in Saudi Arabia. Makkah Al-Mokarramah houses "The Islamic Jurisprudence (Figh) Council of Islamic World League of the Organization of Islamic Countries", with members representing Islamic States. In this article, this source of guidance, in addition to relevant verses of Qura'n and the Hadeeths are followed.

Cultural awareness and contextual knowledge are necessary prerequisites for health care in culturally sensitive communities with strong societal values and beliefs, as is the case in Islamic communities. An appreciation of the societal values and beliefs must be reflected in all aspects of life as well as in individual and family interactions. In Islamic countries, as well as among Islamic communities in non-Islamic countries, Islam continues to influence the societal conduct of life and customs of an estimated one fifth of the inhabitants of the globe ¹⁹ (Figure 2)

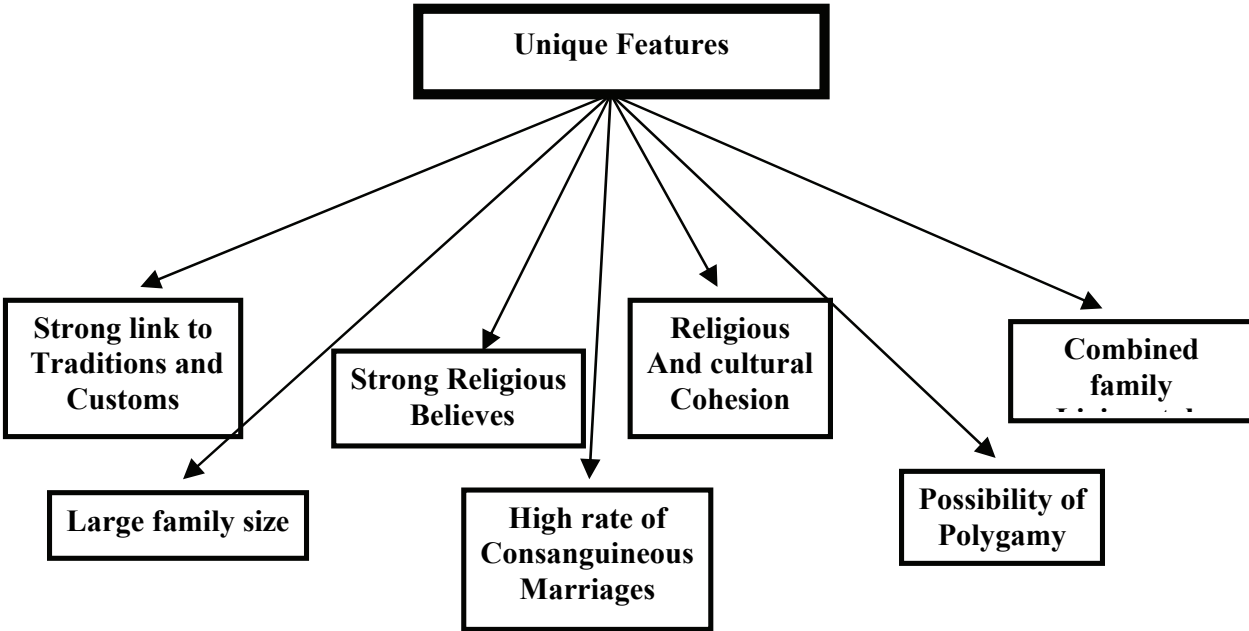


Fig. 2. Arabic/Islamic Communities – Pattern of life

In Islamic Teachings, preservation of the five necessities, “Magasid Al-Sharea'h” represents the respect for human being and human life²⁰. The five necessities are:

1. Maintenance of religion (A-ddeen) ; including the five Pillars of Islam .
2. Maintenance of self (Al-nafs) ; including Human Dignity Prohibition of abortion and fetus rights to survive Prohibition of Killing and suicidal .
3. Maintenance of brain – intellect (Al-aql) ; including education freedom of intellect and research .
4. Preservation of Progeny (Al-nasl) ; including encourage of marriage and prohibition of adultery .
5. Preservation of wealth and honor (A-tharwal wa , Al-erdh) ; including freedom of commerce and offering of Alms "A-Zakat " to the needy .

In addition, varieties of costumes and traditions that, over the years, became part of the Islamic community practices and any instruction contrary to them looked at with suspicion.

3. Genetic screening and counseling as means of prevention of genetics diseases

The genetic disorders can give rise to chronic diseases that currently have no or limited definite cure. Preventive measures of genetic diseases, particularly at an earlier stage, proved to be of practical value. The main pillars of prevention are genetic screening and supportive counseling. Genetic screening or testing can be carried out at different stages, as follows^{25 - 27}:

- Age of puberty
- School age
- Post-natal screening
- Screening during pregnancy
- Pre - implantation Genetic Screening - before implementation and after *in vitro* fertilization (IVF).

Genetic counseling is considered an important complementary approach to the screening procedure. As a service, it is offered to the members of the high risk groups, i.e. carriers of recessive genetic disease or those with an affected member of the family.^{25 - 36}

As a profession, the genetic counseling demands certain ethical frameworks that are required by the very nature of the function of the counselor. Being considerate and compassionate should complement the counsellor and colour the communication with the client. The counseling process should be nondirective, where the decision-making should lie in the hands of the person concerned, but to be based on full understanding of the genetic situation and the pros and cons of the outcome of the probable condition. The principles and components of the "Informed Consent" that are generally acceptable in western countries are also applicable to Muslim community^{28 - 44}. However, Muslims, in general, will often want to consult with family members and religious scholars, particularly in aspects of religious and social relevance.

4. "Islamic Teachings" on prevention of genetic disorders

Ethics in medical practices, within the framework of Islamic teaching, emphasizes the importance of educating the people and raising their awareness of the pattern of inheritance, its implications and the available means of prevention and care. On prevention side, pre-marital screening seems to be the preferable means of choice and appropriate counseling that takes into account the religious beliefs and prevailing traditions can be effective. These practices are carried out in a number of Islamic Countries and considered the method of choice in prevention of Single Gene Disorders. Similarly, neo-natal testing, avoiding of teratogenes and provision of folate and iodine in the diet is encouraged as supportive measures. On the care side, drug treatment, supportive care, Stem cell and gene therapy are welcomed.

Islam pays special attention to the reproduction of mankind and the maintenance of human race on earth. One of the necessities in the Magasid Al Shareah is that progeny is to be protected throughout life, namely pre-marital, pre-conception, pre-natal, natal and post-natal stages. At pre-marital stage, selection of the parent (man/women) includes that the parent should be healthy, and perform a good deeds. At pre-conception stage, Islam prohibits any attempt to tamper with the productive process. At natal stage, Islam prohibits abortion after the fourth months of pregnancy, i.e. after the Spirit is blown into the foetus.

Thereafter, the parents should appropriately care for the newborn including advocacy for breastfeeding until two years of age. The parents looking after the children should include observing their rights of having a decent, peaceful and worthy life.

5. Directions regarding abortion of the genetically affected foetus

"The Fatwa" number 4 of "The Islamic Jurisprudence Council of Islamic World league of the Organization of Islamic Countries", at its 12th session,⁴⁷ allows for the option of abortion under certain specific conditions. The fatwa determined that the abortion may take place only if a committee of specialized, competent physicians has decided the foetus 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). Beyond 120 days, i.e. after the spirit blown into the fetus, abortion only is allowed if there is a danger threatening the mothers' health.

6. The "Sharea'h" views toward human genetic research outcome and use

In Islamic communities, genomics research and the applications of its outcome into medical practices, are conducted within the context of culture and religion framework. In this respect, 'The Islamic jurisprudence Councils in Islamic Countries' paralleled the scientific advancements in looking into the usefulness of the genetic research outcome to human kind. "The Islamic Jurisprudence (Figh) Council of the Islamic World League of the Organization of Islamic Countries" in Makkah Al-Mukarama and The High Council of Al-Ulama" of Saudi Arabia, as well as similar bodies in other Islamic Countries, as the need rises, discuss and pass guidelines and "Fatwas" of the Learned, an authoritative ruling, on subjects of general concern to Islamic communities. The decision making leading to the Fatwas and the guidelines, are based on information provided by professionals and experts in the relevant field under discussion.

7. Guidelines on the use of genetic information and technologies in the management of genetic diseases

"The Islamic Jurisprudence Council of the Islamic World League of the Organization of Islamic Countries", in its 15th session gave the following guidance on the use of the genetic information and research technology ⁴⁵:

1. allow the use of genetic engineering for disease prevention, treatment, or amelioration on the condition that do not cause further damage;
2. forbid the use of engineering in evil and criminal use or what is forbidden religiously;
3. forbid using genetic engineering and its tool to change human personality and responsibility, or interfering with genes to improve the human race;
4. forbid 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 Sharea'h;
5. 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;

6. call on biotechnology companies and food and medical factories to reveal the structure of these bioengineered products so they can be dealt with and used with caution in light of potential harm or if any are forbidden religiously;
7. recommend all doctors, factory and laboratory owners to fear Allah (GOD) and to watch out for Allah to avoid inflicting harm to humans, society or the environment

8. DNA fingerprinting and its use

On DNA fingerprinting, "The Islamic Jurisprudence Council of Islamic World league of the Organization of Islamic Countries", in its 16th session, issued the following guidance:⁴⁶

1. It is religiously allowed to use DNA fingerprinting in forensic interrogations to prove crime which has no definite penalty in Islamic law (Share'ah) (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 Share'ah.
2. DNA fingerprinting may be used in lineage (genealogy) only with great caution and confidentiality as the Share'ah 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;
 - in case of a dispute about unknown lineage, as mentioned by the Islamic scholars because the evidence is either absent or equivocal, and to overcome (inundate) the vagueness (suspicion).
 - in case of a dispute over babies in hospitals and nurseries or test tube babies;
 - in case of children lost because of war, accidents or natural disasters, where there family could not be found;
 - to identify babies or prisoners of war.
6. The human genome of an individual, nation or race should not be sold for any reason; neither should it be given because of the harm it can cause. The counsel recommends that:
 - i. the state to forbid DNA fingerprinting testing except on judge's orders and performed in the state laboratories; the private sector should be forbidden from doing such tests because of the great danger and harm.
 - ii. each state should have a committee on DNA fingerprinting tests which should include legal scholars, physicians and administrators to supervise and approve the result of such tests.
 - iii. there should be a precise mechanism to prevent deceit, cheating, contamination or human error in such laboratories, so the results are compatible with reality. The accuracy of these laboratories needs to be confirmed.
 - iv. the number of genes used for a test should be sufficient, in the opinion of specialists, to overcome any doubts about the accuracy of the results.

9. Cloning and stem cell research

"The Islamic Jurisprudence Council of Islamic World League of the Organization of Islamic Countries", in its 10th session,⁴⁸ explored all the research papers and recommendations of the 9th Medical and Fiqh Seminar held by the Islamic Medical Organization during 14-17 June 1987 and agreed on the Decree no. 2/100D 10, which states that:

1. Human Cloning is forbidden in these two (or any other) methods that lead to human reproduction.
2. If the first legal rule is overstepped, the consequences should follow the legal rulings.
3. It is forbidden in all cases to introduce a third party into marriage, i.e an egg donor, a surrogate womb, a sperm donor, or a cloned cell.
4. 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.
5. 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 experimentations on human cloning or promoting it.
6. The Islamic Organization for Medical Sciences and other similar bodies are called upon to monitor all scientific developments in the field of cloning and define its terminology and organize seminars and meetings, as required, to determine and articulate the Islamic rulings and principles pertaining thereto.
7. Specialized committees should be set up to look into the ethics of biological research and adopt protocols for study and research in Muslim countries.
8. Biological and bioengineering research institutions (other than cloning research) should be supported and established, according to the Islamic rulings, so that Muslim world will not be dependent on others in this field.

"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. According to God saying (When there comes to them some matter touching (Public) safety or fear, they divulge it. If they had only referred it to the Messenger, or to those charged with authority among them, the proper investigations would have tested it from them (direct). Were it not for the Grace and Mercy of Allah unto you, all but a few of you would have fallen into the clutches of Satan (The Holy Qura'n, Sorat Al Nesae, Ayat 83)".

After listening to the research papers and the opinion of the Council members and the experts with relevant knowledge, the Council made the following decree:

FIRST: It is permissible to obtain stem cells, to be grown and used for therapy or for permissible scientific research, if its course 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 umbilical cord, with the permission of parents.
4. a fetus is spontaneously aborted or when aborted for a therapeutic reason permitted by Shareah, with parents' permission. (Be reminded of decree No. 7 of the counsel 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".

10. Conclusions

Islamic teachings in all aspects of life are drawn from the Holy Book of all Muslims (The Qura'n), the Prophet (PBUH) speech (The Hadeeths), then Consensus (*Al ijma*) and Analogy (*Al Qiyas*), resulting in "Islamic Jurisprudence". Where appropriate, consideration is also given to public interest "*Maslaha*" through the decision of the Learned, i.e. the "Fatwa", and local customary precedent, i.e. "The *urf*"⁴⁹.

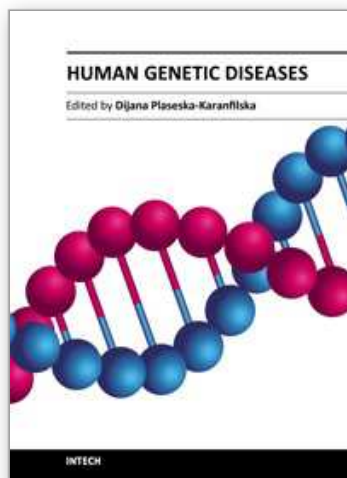
Bio- and medical ethics are extension of Sharea'h, where decision-making observe Magasid Al-Islam, that emphasizes the need for preservation of the components of human being and the patterns of human life. In these principles, Islam shares many foundational values with the other Abrahamic religions, Judaism and Christianity, where similar teachings are given⁵⁰⁻⁵⁴. Of relevance are these religions teachings regarding the restriction on abortion and the wrights of the foetus. Like other religions, Islam has diverse sects and, therefore, diversity of views in bioethical matters does exist. However, there is little that is controversial, concerning pre-natal diagnosis and abortion of the malformed or genetically disordered foetus. The Islamic Teachings in medical practices, particularly those related to genetic services as outlined in this article, are not meant to be exclusive, where there may be different opinions based on other "Fatwas", or sources related to other Islamic sects. It is hoped that the insights gained from this presentation will aid clinicians and other health care workers providing genetics services to better serve their Moslem patients, their families and the whole community and deliver care that pays due respect to their beliefs, customs and prevailing traditions.

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Human Genetic Diseases

Edited by Dr. Dijana Plaseska-Karanfilska

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The genetics science is less than 150 years old, but its accomplishments have been astonishing. Genetics has become an indispensable component of almost all research in modern biology and medicine. Human genetic variation is associated with many, if not all, human diseases and disabilities. Nowadays, studies investigating any biological process, from the molecular level to the population level, use the “genetic approach” to gain understanding of that process. This book contains many diverse chapters, dealing with human genetic diseases, methods to diagnose them, novel approaches to treat them and molecular approaches and concepts to understand them. Although this book does not give a comprehensive overview of human genetic diseases, I believe that the sixteen book chapters will be a valuable resource for researchers and students in different life and medical sciences.

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