Human Genome: Social and Ethical Implications

İNSAN GENOMU: SOSYAL VE ETİK ANLAMLARI

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Summary

The Human Genome Project is possibly the most important and interesting Human achievement. Application of human genome in health and medicine has an important role in taking preventive measure, devoloping new diagnostic tests and better treatment, correcting the faulty gene by gene therapy.

In this paper historical and political background to human genome; privacy, confidentiality and fairness in dealing with genetic information; reproductive, psychological, philosophical and conceptual implications and biothical and Islamic view are vovered. Also, there are some Muslim scholar's views on human genome implications. The following headings are privacy of genetic materials, psychological implications, pre implantation genetic test and genetic determinism.

Key Words: Human genome, Ethical implications, Social implications

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Özet

İnsan genomu projesi, insanın belki de en önemli ve ilginç başarısıdır. İnsan genomunun sağlık ve tıpta kullanılmasının önleyici tedbirlerin alınmasında, diagnostik testlerin ve daha iyi tedavilerin geliştirilmesinde, gen tedavisi ile hatalı genlerin düzeltilmesinde önemli bir rolü vardır.

Bu makalede, insan genomunun tarihsel ve politik geçmişi; genetik bilgi ile ilgili gizlilik, sır saklama ve adaletli davranma; reprodüktif, psikolojik, felsefi ve kavramsal anlamlar ile biyoetik ve islami bakış aktarılmaktadır. Ayrıca, bazı islam alimlerinin insan genomunun anlamları üzerindeki görüşleri yer almaktadır. Belirtilen başlıklar genetik materyalin gizliliği, psikolojik anlamlar, pre implantasyon genetik testi ve genetik determinizmde insanın iradesidir.

Anahtar Kelimeler: İnsan genomu, Etik anlamlar, Sosyal anlamlar

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1. Introduction

Allah "God" bestowed upon us the faculty of the intellect "Aqil" and has commanded us to ponder over his creation, observing profoundly the signs of his power and his glory throughout the entire universe and within ourselves. It is stated in Qura'n " We shall show them our signs on the horizons and in themselves, until it is clear to them that it is the truth. (Ch.41:53) (1).

The Qura'n encourage the direct empirical observation of the natural phenomenon in order to acquire more knowledge of it. This induced Muslim scientist to adopt this empirical inductive method in scientific research from the closing years of the seventh century AD.

By the middle of the 8th Century an extraordinary Muslim scientist Jabir ibin Haiyyan wrote a scientific procedure "as we refer to nowadays" in Chemistry laying down the ten classical rules for performing an experiment. Which are as valid today as they were in the dawn of the age of scientific enquiry.

This empirical inductive method in scientific enquiry travelled to the west through the gate of Spain and Sicily. These testimonies are according to some western intellects like John William Draper in his book "The Intellectual Development of Europe" and Stanley Lane Poole in his book "Moors in Spain"(2,3).

Those scholars refer clearly to the intellectual impress of Muslim on Europe.

In order for Muslims to retain their role as trustees for God, they have to work hard and find their path among other nations. Since the current civilisation is based on science and technology and the western countries listen only to the voice of science, and empirical evidence, Muslims have to invest in science and be able to solve the current problems resulting from the implications of the new technology. We Muslims have to participate in solving the problems of Greenhouse effect, Global warming and pollution. Muslims have to participate in finding solutions for the adverse implications of Biotechnology, and identify desirable applications of Genetic engineering in animals, plants, Human, IVP and finally the Human Genome and its ethical, legal, and social implications. We should, as Muslims, indulge and participate effectively in the current scientific research on the one hand, and be in a position to offer a moral, ethical code of practice based on wisdom, faith and shariah on the other hand (4,5)

This humble paper is to raise an awareness among Muslims to this new genomic era and its ethical, legal, social and religious implications.

2. Definition

The Human Genome Project (HGP) is possibly the most important, interesting and really inspirational Human achievement. It is also a technological victory, and many described it as more significant than the invention of the wheel or landing the man on the moon. This code "Human Genome" is the essences of mankind's life and as long as Human exist, this information is going to be important and will be utilised.

46 chromosomes constitute the Human Genome. This Genome contains about 30.000-40.000 genes (functional genes) which make up only about 3% of the total genetic material, as recently discovered (6,7). The rest referred to as junk genes.

The first aim of the HGP was to determine the location of all 40.000 genes on the 46 chromosomes. The second aim, which follows from the first one, is the determination of the base sequence of the Genome to identify the function of the genes. To find the location of the gene, a process known as mapping is adopted, and sequencing is to determine the base sequence of the gene.

The dimensions of the project are difficult to imagine due to delicate and sophisticated processes involved. This is mainly due to the huge size of DNA molecule. It is estimated that the length of DNA molecule in each cell in our body is around 2 meter. Given the fact that Human body has an average of 100 trillion cells, thus if all the DNA in our body are attached to each other and stretched, it will reach the moon and back to earth eight thousand times.

To simplify the ethos of Human Genome Project (HGP), it will help to draw the following analogy:

If we magnify the size of the nucleus of the Human cell to the circumference of the earth, then one chromosome would have the dimension of a country. A gene would have the dimension of a city. The base pairs would have the equivalent of the population of that city. In this "world of the cell" scientists are looking for round 30.000-40.000 genes (cities) to locate them on the 46 chromosomes (countries) and ultimately to find out the sequence of a line of 3 billion bases (inhabitants).

3. DNA Molecules

In simple terms DNA molecules structure is composed of:

Sugar dexoyribose

Phosphate

Nitrogen (nucleoside) bases of which there are 4 kinds–Adenine complement Thymine and Guanine complement Cytosine (A-T and G-C).

The structure resembles a twisted spiral staircase usually referred to as double helix, with sugar-phosphate backbone to the outside and are held together by hydrogen bonds between complementary bases resembling the steps.

The main functions of DNA molecule are:

1. Storage of genetic information, where all the information required to produce and maintain a unique organism are contained within DNA

2. Inheritance, The information stored in DNA is transmitted to all descendent.

3. Expression of genetic message, the information stored in DNA molecule is transcribed and translated into specific proteins that are required by the cell.

The way in which genetic information is stored, inherited and expressed is basically the same in all-living organism. **This explains the uniformity of creation and uniqueness of creator.**

Since we dealing with lettering system we might draw this analogy used by (8), to make it simple for people not familiar with biochemistry.

A simple "message" in English encoded in a linear sequence might be:

TTHECATSATANDATETHERATANDRANOFF

It become more intelligible if a "reading frame" of three letters to each word is imposed upon the linear message as in Fig (1). You will get a complete sentence, which have a meaning and could be compared to a normal protein (Fig 1. A).

If a single error (italic letter) is introduced into the message as in (B), which we refer to in genetic as mutation. Then after segregation into three-letter frame, the sentence lost its meaning. This illustrates the delicate and the sophisticated manner that the DNA molecule works within. Giving the fact that each Human cell contain 3 billions of genetic letter any error in any single letter will led to mutation which sometime could be fatal and most times lead to different genetic diseases as in sickle cell anaemia.

Currently there are more than 4000 genetic disease resulted from changes to a single gene. Most of these changes are rare, but many causes sever suffering and often lead to early death.

The number of people affected by genetic diseases world wide is roughly 2% of all live births every years (9). Most of the genetic mutations are maintained in the population by the passage of the genes from parents to offspring, or by steady input of new mutations. Not all the genetic anomalies run in families, some may results during the formation of gametes (sex cells), or in the early development of foetus or even exposure to radiation or other chemical agents

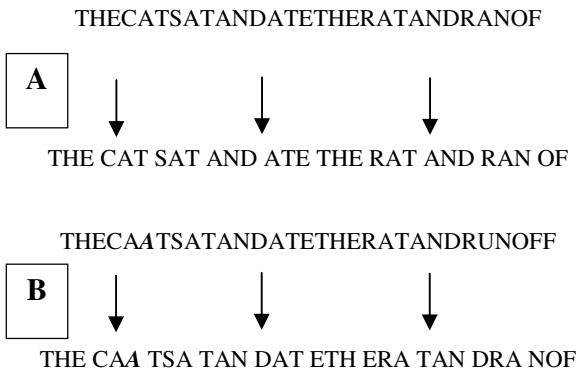

Figure 1. Analogy of gene language

Steve Jones in his brilliant book "The language of the Gene", the winner of the Rhone-poulence prize of 1994 described genetics as follow: *"genetics as a language, a set of inherited instructions passed from generation to generation. It has a vocabulary–the genes themselves- a grammar, the way in which the inherited information is arranged, and a literature, the thousands of instructions needed to make a Human being. The language is based on the DNA molecule"* (10).

Bill Clinton President of the United States joined Tony Blair the Prime Minister of Britain in praising the feat at a satellite-linked press conference on 6/6/00. He announced *"Today we are learning the language in which God created life. We are gaining ever more awe for the complexity, the beauty, the wonder of God's most divine and sacred gift"*. (The Daily Telegraph, 7/6/00).

4. Application of HG in Health and Medicine

The following is only bullet points to highlight the huge benefit of Human genome application in health and medicine:

4.1. Preventive Measure: The sequencing of the Human Genome and ultimate knowledge of the all genes in the next decades to come will lead to a fundamental shift towards preventive medicine. It is predicted that in 2010 genetic tests would be

routine practice, where blood samples are taken to extract the DNA materials. This material then screened to determine the risk of developing various diseases.

4.2. Develop New Diagnostic Test: As a result of accumulation of large numbers of newly discovered genes as a consequence of Human Genome project's efforts, scientists developed a new tool called "DNA chip" also known as "DNA microarray". What silicon chips have done for computers, DNA chips may do for biological research.

4.3 Develop Better Treatment or Personal İsed Medicine: Decoding the 3 billion letter of the Human Genome will without any shadow of doubt revolutionise the treatment in 21st century as much as antibiotic did in mid of 20th century, and even more. Scientists will be able to predict inherited predisposition to various diseases and to be able to design tailor-made drugs. The information that the Genome provide will facilitate the development of personalised medicine, with each patient being treated according to his unique genetic make up.

5.4 Correcting the Faulty Gene by Gene Therapy: "Gene therapy" is the use of DNA to correct a genetic defect at the DNA level. Over the years, much has been written by many scientists about the great promise of this form of treatment, and the ethical issues surrounding it. Despite evidence of measurable success, gene therapy has in recent times attracted increasing scepticism because of its failure to deliver its promise 15 years of intensive research.

Clearly, the day of gene therapy is not here yet, and more focused research will be required to develop, above all, efficient and safer gene-delivery.

6. Social and Ethical Dimensions of the Human Genome

The Department of Energy and the National Institutes of Health have allocated 3-5%, which is around £120 million dollars of their budget to study, analyse and address the ethical, legal and social implications surrounding the availability of the genetic information.

To discuss these important issues, the following topics will be covered in little details:

1. Historical and Political background to Human Genome
2. Privacy, Confidentiality and fairness in dealing with genetic information
3. Reproductive implications
4. Psychological implications
5. Philosophical and conceptual implications
6. Bioethical and Islamic View

6.1. Historical and Political background to Human Genome: Large numbers of people from scientific and non scientific circles are very concerned with the great development in genetic sciences and are afraid of the memory of eugenic movements in Nazi Germany, rest of Europe and United State during the first half of last Century. If the development in modern knowledge of Human Genome is aimed to benefit Human being rather than harm them, there must be an awareness and understanding of the lessons of history among the scientific circles and society at large. Those lessons of Eugenics movement, which used some, distorted scientific data to justify its ideology and inflicted misery among wide spectrum of people across the civilised world!

6.2. Privacy, Confidentiality and fairness in dealing with Genetic Information: The most critical issue of social implications of the Human Genome is the privacy, confidentiality and the fairness in the use of the genetic information.

Rothstein of the University of Houston, Law centre define "Privacy" as the limited access to a person, the right to be alone, and the right to keep certain information from disclosure to other individuals.

Confidentiality, on the other hand, is the right of an individual to prevent the redisclosure of certain sensitive information that was originally disclosed in the confines of a confidential relationship. Protecting confidentiality can be difficult because others think they should have the right to see an individual's information (11). In Hippocratic oath, first mentioned the "duty of confidenti-

ality". The need to maintain the confidentiality is considered as an ethical obligation in the relationship between the patient and his doctor. This obligation facilitates the openness and frank communication between the two parties. This help immensely in the diagnosis and treatment of the patient. The patient is reassured that his dialogue with his doctor would remain confidential and any documented information would remain secret. This is in legal term, may be considered as an aspect of patient's right to privacy (12).

Unless safeguards are established, we all run the risk of being victims of genetic discriminations on various levels, employment, insurance, ethnicity, education, courts, military and many others. American president Clinton acknowledged the benefits of the Human Genome project, but warns against the misuse of genetic information, in his announcement in 1997 for the support of legislation to provide comprehensive solution to the problem of genetic discrimination. He said, "*Genetic discrimination is more than wrong. It is a life – threatening abuse of a potentially life-saving discovery".*

6.3. Reproductive Implications: The implications of Human Genome Project on reproduction arise from the highly probable alliance of Medically Assisted Reproduction (MAR) with Diagnostic Genetics (DG). This alliance was referred to nicely by new term used by (13) as Reprogenetics. This term comes from the merging of remarkable scientific and technological advances in two fields-Reproductive Biology and Genetics. This new field will turn science fiction into reality from cloning to embryo selection to genetic engineering and beyond. It also raises serious ethical and legal questions (14).

Currently the medically assisted reproduction aims to help infertile couples through different techniques to have children.

6.4. Psychological implications: The genetic information will be accumulated as a result of Human Genome project and consequently result in expansion of genetic testing. The genetic testing will expand beyond single gene disorders, to testing for genes associated with common disorders, thus it is very crucial to take into consideration what impacts this will have on the psychology of the individuals, their families and the society as a whole. The psychological implications of genetic screening for genes associated with increased risk of certain diseases has been well studied and researched (15). Currently most of the genetic screening is carried out in prenatal or preimplantation stage to ensure the safety of the future children, but predictive tests, which allow people to know their possible predisposition to certain diseases are increasing frequently as genetic information accumulated.

The completion of Human Genome sequence will facilitate the identification of all the genes that contribute to diseases. The functional classification of disease gene and their products will reveal general principles of Human diseases.

Many in the medical establishment believe that uncertainties surrounding test interpretation, the current lack of available medical options for these diseases, the tests' potential for provoking anxiety and the risks for discrimination and social stigmatisation could outweigh the benefit of testing.

Philosophical and conceptual implications

Since the dawn of history, the argument of Human responsibility, free will Vs genetic determinism is occupying a large area in Human thinking. If the theologians and philosophers discuss this issue logically, the Geneticists and in particular behaviour geneticists are tackling this vital issue experimentally. They are trying to proof whether people's genes make them behave in a particular way? Or can people always control their behaviour? And what is considered acceptable diversity? In answering these questions the scientist do differ, some proof it this way and others believe it the other way. Some believe that the gene makes us Human and the notion of "genes are us" provides a sensational media items these days. We heard on a daily basis that they found a gene for aggressiveness, homosexuality, alcoholism and even promiscuity (16)! We heard that the genes

make some musicians, Olympic athletes, or genius and make others schizophrenics, manic-depressives, even drug addicts. Moving in this slippery road will inevitably led us to the memory of Eugenic movements in first half of 20th century. Where the reliance on a distorted scientific data and promoted it as an ideology caused tremendous misery among wide spectrum of people across the civilised world!

Single genes do not determine most Human behaviour. Only certain rare disorders such as Huntington's disease have a simple mode of transmission in which a specific mutation confers the certainty of developing the disorder. Most behavioural traits have a more complex aetiology, known as complex traits.

Behaviour is a sophisticated aspect of Human attributes because it is the product of the most complicated organ in the Human body, the brain.

The genetic basis of many aspects of Human behaviour is very difficult to assess due to the fact that a human's behaviour is not a constant physical entity, but rather extremely dynamic and continually changing all the time. This changing potential gives the Human being an immense capability to adapt to divers environment and increased his survival opportunities. Thus, no wonder the genetic basis of Human behaviour is still poorly understood.

6.6. Bioethical Implications and Islamic view: The speed of innovation in biology and in particular genetic engineering research is so fast that it will outrun peoples' ability to grasp, adapt and adjust to it in a sensible and rational way. The world lacks the mechanisms to come to term with these sophisticated discoveries. This explains the setting of a wide spectrum of committees, authorities and institutions to deal with different bioethical questions that resulted from the development in this research.

Ethics is the way to deal with extremely difficult questions of right and wrong. It is the study of moral value of Human conduct and of the rules and principles that govern that conduct. It is often referred to as moral Philosophy.

Basic categories of ethical concern fall into two classes:

1- Intrinsic Concern that deals with things that is thought to be wrong

in themselves such as nuclear weapon or Human cloning.

2- Extrinsic Concern which involve the application of the technologies.

They are neutral in themselves, but open to misuse or cause harm to others, such as genetic engineering that can be used to treat disease or it could be misused to create biological weapon. Though other scientists believe that genetic engineering is also intrinsically wrong (17).

Islamic jurists vary in their verdict towards recent developments in genetic engineering and in particular cloning, ranging from total rejection to giving cautious and conditional acceptance (18).

6.6.1. Some Muslim Scholar's views on Human Genome Implications: I put forward a number of questions relating to the implications of Human Genome to a number of Muslim scholars in the Muslim world. I first explained to them preliminary information as background to help them in formulating informed views. My questions were grouped under the following headings:

- Privacy of genetic materials
- Psychological implications
- Pre implantation genetic test
- Gene patenting
- Human will vs genetic determinism

I received quite a thoughtful response form some of the scholars (at the time of writing this manuscript) who are kind enough to spare some of their precious time to respond to my quires.

All the scholars who responded encourage the genetic research, which facilitate the diagnosis and the treatment of the diseases.

Fazlullah of Lebanon responded to the questions as follows:

(1) The genetic substance is a formative peculiarity for its bearer as part of his formation, fundamentally the others should not be informed

about this peculiarity if it represents a formative defect which its bearer does not want the others to know about, unless in cases of relieving harm from him or advising others. If it is not a defect (*however*), then there is no prohibition on talking about it without his permission. This view also shared by Al Harandi and Al Jawahri of Iran, in addition to Alsanad of Iraq.

(2) It is not obligatory to inform him about what the substance leads to of future psychological illness. In fact it (*becomes*) prohibited if this puts him in the negative psychological effects at the present (*i.e. the negative frame of mind*), as a result of the reaction to this knowledge with his self/personal feelings. (*However*), if informing him about these (*consequences*) conforms to the possibilities of carrying out a preventive measure, which will protect him from future harm, then there is no prohibition. Aljawahri has the same view.

(3) It is prohibited to carry out abortion simply because it has become known that the foetus suffers from a dangerous illness, especially if after the soul has been infused into its body after the foetus attains 120 days. Abortion prohibited once this stage is attained, except in extreme condition when the life of a mother is at high risk. Before 120 days abortion may be tolerated-according to to reasonable number of scholars–for a reason acceptable to the sharia, such as the case of untreatable sever congenital anomalies and only with the consent of parents. This is shared by many other scholars (19-21). Though Aljawahri and Alharandi believe that abortion is prohibited before and after 120 days, and only permitted if the mother life is at high risk.

(4) The mere knowledge of the company about the gene does not give it the patent so as to have this knowledge (*as a knowledge*) possession to the extent that the owner who himself owns the gene is prohibited from acting freely with. Al Harandi have the same view, whereas Alsanad believed that the company have the right to patent the genetic material provided it get a contractual agreement for that.

(5) Genetic peculiarities, exactly like all living elements within the body, can leave their negative or positive effects on man by preparing the psychological, mental and practical circumstances to move in their direction. ? But they are not outside the preparation for that–this preparation which may clash with the Human will power, which may be affected by the peculiarities of the knowledge coming from outside or the objective circumstances which is surrounding the self–which may lead to some practical activities that may change some of these effects. At any rate, choice is not distant from personal effects within the Human formative peculiarities, but it has something else of the Human nature, in the depth of the instinct that Allah, the Most High, amassed in it. **This means that whatever effect the genes have, they do not represent the causative inevitability in the consequences so as man loses choice;**. All the Scholars agree that genes have no overriding power over the Human will, and Allah the Most High is the Knowing.

I believe that the above-mentioned views still need to be debated and discussed further across the Islamic scholars and scientists to provide a solid and reliable background to refer to in this very fast advancing field of genetic research. I also believe that there should be a consultative body within the Muslim countries with diverse expertise (social, science, law, and religious scholars) to debate these crucial issues and put recommendations to decision making bodies concerning this research within the spirit and purity of Islamic Sharia.

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