

Reprogenetics and Genetic Counseling: Scientific and Ethical Implications

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Genetic research and knowledge has grown to unsurpassed dimensions in the past decade. The Human Genome Project (HGP) showed that humans are made up of about 30,000 to 40,000 genes. The genetic background of many diseases and conditions could now be elucidated.

A conglomeration of factors plays significant roles in dealing with the widespread implications of these new genetic breakthroughs, including ethical, religious, psychosocial, economic as well as medical and scientific dimensions.

It is conceivable to use this new information to detect significant disease states, to undergo genetic counseling with individuals or families and to reach acceptable decisions as to how to deal with them. Examples of such conditions include prenatal, or the more recent preimplantation diagnosis, as well as genetic counseling of sickle cell disease, thalassemia, hemophilia, cystic fibrosis ... etc.

Pre-implantation Genetic Diagnosis (PGD) has been developed to identify serious genetic diseases in human embryos (or pre-embryos) before transfer to human uterus. Only embryos not affected by the specific genetic disorder could be transferred to the uterus.

This was a major step forward to the previous Prenatal Diagnosis (PND), which involves identification of genetic and other diseases during pregnancy, by using ultrasonography, amniocentesis or villous sampling. Fetuses affected by significant genetic diseases could then be aborted. Such decisions have always stirred strong ethical and religious opposition.

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This is the classic aspect of the whole issue of new genetic discoveries. There are many other aspects that are very controversial! The Human Genome Project enables us to discover the genetic background of conditions like intelligence and physical features such as height, color of skin, color of eyes ... etc.

Other conditions such as depression, schizophrenia, rheumatoid arthritis, certain tumors and autoimmune diseases, may be inherited.

Who is to decide on preventing or terminating a pregnancy, if the embryo or pre-embryo, carries the faulty gene(s)? Some other consequences derived from the HGP implications include many extremity sensitive situations. The so-called presymptomatic diagnosis (or susceptibility testing) refers to the identification of healthy individuals who may have inherited a gene for a late-onset disease, if they live long enough; e.g. Huntington disease, heart disease, Alzheimer disease or certain cancers. Who has the right to inform the patient about the existence of such genetic predisposition? Do we need to enter this issue in the first place? Does the society at large need to undergo screening for these conditions? The knowledge that the future development of such diseases is inevitable could put a heavy burden on peoples' every day existence and well-being and might change their personalities.

Living with knowledge that one has the strong possibility of developing a malignant tumor by the age of 40 or 50 may be unbearable!

On the other hand, some future serious diseases may be prevented or decreased by changes in lifestyle or environmental modifications, such as diabetes, atherosclerosis and others. In these conditions, screening may bear some benefit.

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In the area of prenatal and preimplantation diagnosis of inherited diseases (and conditions) in embryos, or pre-embryos, there are genuine ethical and religious implications. What are the pathological conditions that justify the termination of pregnancy, or justify the selection of the pre-embryo, in IVF centers, that could be used for conception? If certain conditions (e.g. schizophrenia, depression, rheumatoid arthritis, certain tumors or autoimmune diseases) are proven to be inherited, could the pregnancy be terminated?

The other extremely sensitive and complex question is related to how to keep the privacy and confidentiality of this genetic information. If this issue is not properly and carefully taken care of, subjects with certain "faulty genes" could be stigmatized and discriminated against, in employment, insurance, schools and social relationships.

Some other disadvantages are repeatedly cited by human rights defendants. In view of the high cost of genetic screening and testing programs, and their future medical utilizations, it is conceivable that only privileged individuals and societies could benefit from them. The complex issue of Eugenics is another serious concern. Eugenics is a term that have been used for several decades, which involves selection of certain features, not necessarily disease related, to improve the physical or intellectual characteristics of certain individuals or races. Using the genomic revolution in this manner was deemed unethical for a long time. It also could widen the differences among social classes, as well as between wealthy and poor nations. To the already prevalent unjust distribution of wealth and social advantage, mankind could face injustice in genetic qualities!

In summary, recent and revolutionary advances in genetics have far-reaching consequences in both medical and psychosocial aspects of people. There is a crucial need to formulate sound ethical and regulatory standards with due consideration to faith and religion.

It is pertinent to list here some recommendations of some workers in the field. Most of these recommendations are consistent with Fatwas and religious-ethical opinion by our Islamic councils:

1. Pre-implantation genetic diagnosis is morally acceptable to diagnose severe genetic disorders. It should not be used to diagnose benign disorders.
2. Sex determination by pre-implantation genetic diagnosis is morally acceptable for the diagnosis of sex-linked chromosome disorders, but not for the selection of a preferred sex for non-medical reasons.
3. Pre-implantation genetic diagnosis should only be available in the context of structured clinical trials approved and monitored by research ethics boards.
4. Discrimination against people living with disabilities, those choosing to have children with genetic disabilities and those carrying potentially harmful genes is morally unacceptable.
5. Pre-implantation genetic diagnosis should not be used to promote eugenic practices.

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آفاق طبية

الإنجاب والجينومات والتوعية الوراثية: الأبعاد العلمية والأخلاقية

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لأمراض وراثية خطيرة مثل مرض الثلاسيميا ومرض الدم المنجلي، والناعور والتليف الكيسي وغيرها. ولا بد أن نشير هنا أن تشخيص الأمراض الوراثية قبل العلوق يقوم على الفحص الجيني المخبري لخلايا البويضة الملقحة وهي لا زالت في مرحلة ست أو ثماني خلايا، وذلك في مراكز المساعدة على الإنجاب، وقبل نقلها إلى رحم الأم. وبذلك يمكن نقل اللقائح الخالية من الأمراض الوراثية المعنية، وتجنب نقل اللقائح ذات الجينات الممرضة.

وقد كان هذا خطوة هامة إلى الأمام بالقياس إلى الإجراء الآخر، وهو اكتشاف تلك الأمراض الوراثية لدى الجنين في الأسابيع والأشهر الأولى من الحمل، ثم التفكير بإنهاء الحمل، مع ما يحمله ذلك من عقبات واعتراضات أخلاقية ودينية وغيرها. غير أن هذا القدر من التطور في علم الجينومات يمثل مقدمة لمجموعات من القضايا المتشابكة. فالإنجاز الجديد يمكن المهنة الطبية من الاكتشاف المبكر لحالات غير مرضية مثل مستوى الذكاء والصفات الجسدية كالتطول ولون الجلد ولون العينين وغير ذلك. كما أنه يمكن أن يظهر أمراضاً

لقد تنامت الأبحاث في مجال علم الجينومات في العقد الأخير إلى آفاق غير مسبوقة. وأظهر مشروع الجينوم البشري أن التكوين الجيني للإنسان يشتمل على ما بين ثلاثين وأربعين ألف جين (صبغي)، كما بين هذا المشروع الأسس الجينية للكثير من الأمراض والحالات.

والعمل لا يزال ماضٍ قدماً لتحديد وظيفة كل هذه الجينات، وكيفية تعاملها مع بعضها البعض ومع عوامل أخرى من بينها البيئة لتؤدي إلى الصحة أو المرض، ومن المتوقع أن يكون لهذا الكشف العلمي الكبير آثار بعيدة المدى على صحة الإنسان في المستقبل، غير أنه سيثير مجموعة من القضايا المتشابكة من النواحي الأخلاقية والدينية والنفسية والاجتماعية والاقتصادية، إضافة إلى النواحي العلمية والعلاجية.

ومن المتوقع أيضاً أن يسهم هذا الإنجاز العلمي في اكتشاف العديد من الحالات المرضية، ويمهد لإجراء توعية وراثية للأفراد والأسر والمجتمعات للوصول إلى قناعات وقرارات مقبولة ومعقولة للتعامل مع هذه الحالات المرضية. ومن أمثلة ذلك التشخيص المبكر، في أوائل فترة الحمل، أو قبل العلوق، في مختبرات مراكز المساعدة على الإنجاب،