Unforeseen Journey: Genetics to Ethics

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Abstract

Genetics is a fast evolving science. Are ethical issues keeping pace with it? This article looks into different various aspects of ethical issues which revolve around genetics. These issues or unanswered questions have been categorized into three types: Research, Diagnosis and Management related ethical issues. An argument in favour of world ethical bodies governing research in human genetics has been put forward.

INTRODUCTION

Science, it is often said, is running ahead of ethics and regulation. Few fields of medicine are developing as rapidly as human genetics. With such developments come new dilemmas and challenges for those working in health care. Rapidly evolving science of medical genetics is leading us to a whole new world of questions, never answered before, relating to the whole idea of being human and doing things restrained by humanness.[1] And more so, this rapidly evolving availability of relatively accurate genetic testing for susceptibility to inherited disease, has raised a number of ethical problems for which societies and healthcare professionals are not well equipped or prepared. As human cloning was in news since late nineties, the issues of medical ethics relating to genetics have become paramount in the context of social and cultural orientation we live in. The paradigms involved directly would be related to different spheres of medical sciences. (Table 1)

Figure 1

Table 1

Paradigms where ethical issues would be related to Medical Genetics:
RESEARCH
Human Cloning, Stem-Cell research, Decoding Human Genome and its implications? Risks?
DIAGNOSIS
Large scale Screening? Financial resources? Social, ethical and psychological consequences of diagnosis? Sex determination? Confidentiality? Insurance?
MANAGEMENT
Gene Therapy? Embryo Stem-Cell transplants? Saviour siblings? Designer babies?

Different countries have different medico-ethical laws keeping in lines with their socio-economic structure but this step-ups already chaotic situation globally.[2] The technique of giving birth to donor babies for the benefit of diseased sibling is legally acceptable in US but was banned in the UK till 21st July 2004 when HFEA took drastic decisions to allow it in special situations. Till now, British couples used to eye America for saviour babies who would donate to help their diseased brother or sister, the technique involves IVF (in vitro fertilization) and PGD (Pre-implantation Genetic Diagnosis).Though IVF is commonly performed in infertile couples but the concept of PGD is still controversial. It is allowed in US for producing saviour babies for the treatment of diseased sibling only.

RESEARCH RELATED ETHICAL ISSUES

Research is a prerequisite for medical science to improve and offer better options for the patients and clinicians treating them; should it be directed in the context of ethical grounds of the people directly involved? Well… Off course! There still remains many unanswered question about research in genetics especially in some controversial issues like human cloning; USA banned it in 2003 and in the UK it is illegal as far as reproductive cloning is concerned according to HFEA's policy, however it would consider research involving embryo splitting or nuclear replacement in eggs but the fetus should not be produced.[3,4] The main dilemma per se revolves around pros and cons of producing human clone and the ethical hitch they bring with it, for example replacing a child who died in an accident for parents; there are thousands of ethical questions which you can think of in this simple case, for example, Identity of the clone as a new person?[5] How would he feel being a replacement for his dead brother or sister? His presence and character were determined not by nature but by what his parents were looking for – is that ethically right? And

foremost if at all it would be permitted, how is the border line for deciding, who should have a clone should be set?

There are other ethical questions which are raised directly in relation to research in human genetics and related science. (Table 2)

Figure 2

Table 2

Few ethical questions related to research in human genetics and its implications
To what extent can a person be said to have a right to an individual genetic identity?
Would the likely cost in terms of failures and/or malformations inevitable in developing a programme of human reproductive cloning be ethically acceptable?
Should research in decoding human genome be used in future to help parents produce 'designer babies'? Or, shall it be used to identify genetic disorders which could be prevented in future generations? Where are the ethically set borders?
How should research done in one part of the world influence the other? How will countries be able to regulate their ethical matters under influence from research done in another country? This gives rise to another set of questions -
Should research in human genetics be regulated globally and should there be common bioethical grounds for deciding what's right and what's wrong?

DIAGNOSIS RELATED ETHICAL ISSUES

Advancement in diagnostic methods has made it more possible for different genetic or hereditary disorders to be diagnosed with more specificity. This has pre and post birth consequences for the very patient, parents, healthcare professionals and also on the resources of the nation. All this leads to new sets of unanswered questions which need lots of thinking and proper assessment before anything could be undertaken. The dilemma here more or less is related to diagnosis of genetic disorders in new born babies or screening for genetic disorders during pregnancy. Laws in majority of western world allow prenatal diagnosis of major genetic disorders like Down's syndrome and offer abortion for the same. But as the list of genetic disorders is growing and becoming inexhaustible, should babies be screened for all genetic disorders and where should the line be drawn in classifying them as benign or serious. For example, if on genetic screening, a fetus is found to be susceptible to Diabetes Type II, what should be done? Should it be aborted? How far parental influence should play a role? If the pregnancy is continued, should parents be counselled about diabetes? If yes, when should the child know he is prone to it? And, should he go on strict life style management from the start of his childhood? Would that be ethical? As you can see that just one case of diabetes is leading to so many ethical questions which need to be addressed before we can actually legalize population screening for it. Some say if we can do a genetic test for a disorder it should be done, so parents have the information. Others say tests for benign disorders are pointless since a positive result would be poor grounds for an abortion. Some feel screening out disorders is akin to rejecting disabled people as valid humans.[6]

Figure 3

Table 3

Few ethical questions related to diagnosis of diseases
Should babies be genetically profiled at birth? If babies were genetically profiled at birth, should this be considered as violation of personal liberty?
Should parents be allowed to make decisions for their siblings and would this decision clash when this child grows up into adult?
What are the implications of a child growing up knowing he has a genetic disorder?7
Should pregnant women be able to have the same genetic tests as women undergoing IVF and other fertility treatments?
Should there be a limit to the disorders a baby can be screened for?
Is counselling sufficient for parents seeking genetic tests?
Could health services take the burden of screening, diagnosing and managing genetic disorders?
Should all babies with genetic disorder be categorized as disabled? Which criteria's should be laid for categorizing them as disabled so that they are eligible for special social benefits?
Whether parents should be able to use reproductive technology to choose the sex of their baby?
How far would confidentiality8 be maintained? And what socio-economical implications will it have e.g. Insurance?9
Should confidentiality be breached in case other members of the family are at risk or need screening?

MANAGEMENT RELATED ETHICAL ISSUES

Management of genetic disorders varies from doing nothing to organ transplant. Treatment of major genetic disorders still remains symptomatic and proper screening leading to abortion. Gene therapy is still in its infancy and will take at least a decade or so for its wide spread use. Ethically, treating any disorder should not arise as many questions as diagnosis and research. But, if technology permits us to determine genetic makeup and enhance our sibling's physical and mental characteristics in coming years, should this be encouraged? Undoubtedly, this would cost dear and common man would not be able to afford it, meaning richer people will have better choice and poorer will have less or none. A varied disparity would evolve in humans, a society of super human versus normal. Gene therapy seems very promising with less ethical strings attached.[10] Though, body cell gene therapy (gene repaired in patient) is less controversial than germ line therapy (gene repaired in embryo).In body cell gene therapy its possible to counsel the patient and take proper consent from him which is not possible in later.

DISCUSSION

Finally, to end this endless thinking of what will happen with humans and there own evolved science, I believe that we, healthcare professionals from all over the world need to sit and evolve an approach to genetics with ethical consideration in mind. Global health care organizations should lead the meet and lay guidelines which should be followed by all the countries. Before moving to genetics, a body of elite professionals and lay persons representing their social background should analyze and then let ethical issues

evolve to make way for genetics for good of man kind.

References

1. Kottow, M.H. [Public health, genetics and ethics]. Rev Saude Publica 36, 537-44 (2002).
2. Parker, M. & Hope, T. Medical ethics in the 21st century. J Intern Med 248, 1-6 (2000).
3. Thomas, C. Preimplantation genetic diagnosis: development and regulation. Med Law 25, 365-78 (2006).
4. Dyer, C. HFEA widens its criteria for preimplantation genetic diagnosis. Bmj 332, 1174 (2006).
5. Burley, J. & Harris, J. Human cloning and child welfare. J Med Ethics 25, 108-13 (1999).
6. Parker, M. & Lucassen, A. Concern for families and individuals in clinical genetics. J Med Ethics 29, 70-3 (2003).
7. Burgess, M.M., Laberge, C.M. & Knoppers, B.M. Bioethics for clinicians: 14. Ethics and genetics in medicine. Vol. 158 1309-1313 (1998).
8. O'Brien, J. & Chantler, C. Confidentiality and the duties of care. J Med Ethics 29, 36-40 (2003).
9. Cook, E.D. Genetics and the British insurance industry. J Med Ethics 25, 157-62 (1999).
10. Lippert-Rasmussen, K. Gene Therapy and Ethics: Edited by A Nordgren. Acta Universitatis Upsaliensis, 1999, 208 SEK, pp 175. ISBN 915544640X. Vol. 28 58-a- (2002).

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