Genomics, Gene Test, Gene Technology: Benefits and Ethical Dangers

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Abstract

On June 26th, 2000, U.S. President Clinton announced that the Celera Genomics program led by J.Craig Venter, and the international Human Genome Project (HGP) led by Francis Collins had both completed an initial sequencing of the human genome – the genetic blueprint for human beings. This is another big step after the identification of double-helix model DNA by James Watson and Francis Crick in 1953. They accurately predicted the order of repeating molecules, known as bases (A, T, G, C) on the DNA strand, gives the genetic information of every living organism. The human genomics information, Book of Life, provides more powerful information for genetic medicine - gene testing, genetic engineering, and gene therapy for treatment of diseases. Yet the impact on the social and ethical effects exist too. Do we own genes? We should consider both benefits and social dilemmas. The outcome of gene research gives another chance to reevaluate our life.

I. Introduction

Scientific develop often affects the social systems and ethical values. Especially, genetic revolution has resulted in tremendous impact on the human beings. The sequencing of human genome has even produced more astonishing genetic adventure. It helps medical and biological professionals know more about the genes in human cells and it provides better roadmaps for human genetic tests and genetic engineering. Genetic revolution opens up lots of very intriguing questions. Both the benefits and the ethical dangers are discussed in this paper.

II. Human Genome

Each cell of humans has 22 pairs of different chromosomes plus and X or Y sex chromosomes. Each pair is made up of one chromosome from the mother and another from the father. Chromosomes provide for all genetic information. The chemical structure on the chromosome is called DNA (deoxyribonucleic acid), which is composed of four different nucleotides abbreviated to A, C, G and T.

There are about 3.2 billion nucleotides in a single human cell. As of today, about 90 % them are sequenced. The length of DNA in the whole body is about 60,000,000,000 kilometers! This is equivalent to the distance to the sun and back 600 times! *The fact that the DNA does not form knots and tangles makes one believe the wonder of the Creator?*

About 3% of the sequences represent the instructions for all of the proteins made in the body, such as insulin or hemoglobin. The remainder regions may act as switches that run other genes on and off. Having the full genetic sequence of the entire genome will allow scientists to view the whole human genetic landscape.

A gene is a certain segment of DNA with specification instructions for about one protein, which affects the color, the hereditary diseases, and even the behaviors. There are about 100,000 genes in a human cell. About 9,600 functional genes are identified. Human genes vary widely in length, often extending over thousands of bases. The difference of DNA between two persons is only about 1%. When some private industries claim the patents of human genomes, one would ask, "*when did they actually invent the genes?*" *Who can have the copyright?*

II. Human Gene Testing

Genetic Errors Cause Diseases

The sequences of genes shape how the child will grow. If there are extra bases or misspelled, or deleted, the cell can make a wrong protein, resulting in diseases, such as Hungtington's disease, cystic fibrosis. In 1983, the first disease gene detected is a gene for Hungtington's disease –a scary neurological affliction. DNA fingerprinting was first adopted in 1984. The benefits will be discussed first. Then ethical and social dilemmas are discussed too.

Benefits

Gene tests can be used in three areas: 1) the dominant hereditary diseases. There are about 3000 to 5000 hereditary disease including Hungtington disease, cystic fibrosis – a problem with lungs, muscular dystrophy, and sickle cell anemia. 2) Predisposed genes known to be involved in cancer, heart diseases and some other chronic diseases. 3) More unbelievably, genes might be related to behaviors.

One good example how gene testing transforms the practice of medicine is a story of hereditary nonpolyposis colorectal cancer (HNPCC). People with inherit HNPCC gene have 80% chance or higher chance of developing colon cancer. In 1993, Richard Kolodner and his colleagues at the Dana Farber Cancer Institute in Boston isolated a MSH2 gene. With the early gene detection, people can adopt a high-fiber, low-fat diet to prevent cancer. They can also start yearly examinations at younger age, and can take necessary precautions including removal of the colon before the growth turns malignant.

In 1994 and in 1995, BRAC1 and BRAC2 mutant genes are discovered and proved to be related to breast cancer by Utah Medical School. The possibility of screening and testing

for breast cancer is real. Over 50 inherited diseases genes have been found. The discovery of several predisposing genes for Alzheimer's disease provides the pharmaceutical industry for drug development too.

The information contained in the genetic code will allow them for the first time to study the interactions of many different genes involved in complex diseases such as cancer and diabetes.

"The completion of HNP is the beginning of the next phase of human biology," says Mike Pallazzola, senior director of Biosystems at Amgen Inc. "Now scientists everywhere can do a lot of things they couldn't do before," he says.

Moreover, the individualizing medicine era is here. The pharmaceutical companies will create drugs tailored to a patient's genetic profile (pharmcogenetics) thereby reducing side effects.

Furthermore, the gene therapy for hereditary diseases is being actively studied. William French Anderson, Michael Blaise, and Ken Culver at National Institute of Health did the

first successful gene therapy on a human in 1990. The disease the team targeted was severe combined immunodeficiency (SCID), often called bubble-boy disease because the patient was encased in a plastic bubble so to be protected from infection.

Ethical and Social Dilemmas

Yet there are several potential ethical or social implications raised by the human gene testing:

- People might be denied insurance because of the results.

- People might be denied employment solely based on the gene tests.

- Prenatal Diagnosis. Do the parents have a right to choose a birth of a baby? *Shall the humans have the right to terminate the lives of genetically unhealthy fetuses*? In one case, even risking a chance of not being paid by a California health maintenance organization, after they found the fetus was carrying a gene for cystic fibrosis, the mother decided to have the child anyway.

James Watson, who discover DNA structure and was awarded the 1962 Nobel Prize in Physiology or Medicine, in 1997 claimed that “Never let the government, not matter how apparently benign, into the process. The potential mother should have this authority. It is she who is likely to be most involved with the upbringing of the child.“

- The eugenics might revive once more in a different form?

  Some people recalling Germany’s eugenic actions fear that there will be racial and class prejudices demonstrated by genetic testing. *Should we play God?*

  However, a famous biologist feels that “working intelligently and wisely to see that good genes – not bad ones – dominate as many lives as possible is the truly moral way for us to proceed.” Also, some assert that it is grossly unfair that some families’ lives are affected by the horrors of genetic diseases. *Who decide what the best qualities of “perfect babies” are*?

- Genetic discrimination. *Can only the rich buy longevity*?

- Genetic privacy and confidentiality.

  Without the written informed consent of an individual, the tests should not be done and should not be disclosed to other family members, employers, insurers, or government agencies.

- Validity of gene tests.

  Are gene tests safe and meet high standard? Are they done by providers with formal trainings? Medical professionals, doctors and nurses need to strengthen knowledge in genetics.

- Genetic worry.

  Even if the genetic results are positive, some of them are not curable as of today. "But, what use is it?" Also, while genes play a role in many disorders, so the environments.

- "Nature" versus "Nurture".

Both of them make us who we are. Do gene shape our intelligence and social behavior? *There are many controversial questions.*

About 5% of the HNP budget was allocated to study the ethic, legal, and social impact. Francis Collins served on an American Association for the Advancement of Science panel on science and religion. Through his efforts, the HGP's Ethical, Legal and Social Implications program has expanded into one of the largest supporters of ethics research worldwide.

III. Genetic Engineering

The manipulation of genes is called genetic engineering. There are two areas: one is molecular cloning and the other area is recombinant DNA.

<u>Benefits</u>

In 1973, Paul Greg, a biologist at Stanford University, developed spice genes and DNA recombinant techniques and was awarded the 1981 Nobel Prize. Through this technique (also called genetic engineering), genetic material can be exchanged between different organisms.

For example, by inserting the specific human gene into bacteria, one can obtain large amount of insulin, which is used to treat human diabetes. In 1978, insulin, the first successful genetic engineering product, is first produced from another organism.

Genetic engineered vaccine is being developed to fight against cancer. Gene therapy to treat cystic fibrosis is being considered.

In order to increase crops, scientists has developed Genetically Modified Foods The soybeans, corns, wheat, potatoes have been modified to resist the insects or other diseases. In 1994, Calgene Inc. of California has developed some tomatoes that will not be rotten. In 1999 Japan has developed high iron genetic rice, which could improve iron deficient problems.

Transgenic pigs – animals with human genes – are already being bred. For example, W.H. Velander at Virginia State University in 1999 managed to extract large quantity of "human coagulation factor IX" protein from pig's milk. This protein can be used to cure hemophilia patients.

Ethical and Social Dilemmas

There are definitely some ethical dangers. As stated in New English Journal of Medicine, when one inserted the Brazil nut gene to the soybean hoping to improve the soybean protein quality, the allergens in the Brazil nuts were also transferred to the soybeans. Because of that, US Pioneer Hi Bred Company has halted this project. *Also, the food chain balance might be disrupted?*

To everybody's astonishment, in 1997 I. Wilmut and his colleague in Scotland announced an exciting experimental result: Dolly the sheep. From the ethical and moral points of view, most people, however, propose that human cloning should be prohibited by law.

In 1999, British physicians urged to examine damages that biowarfare, including military applications of genetic engineering, could do to the human race.

In 1976 George Wald, Nobel Prize winning biologist and Harvard professor, wrote:

> Recombinant DNA technology (genetic engineering) faces out society with problems unprecedented not only in the history of science, but of life on the Earth. It places in human hands the capacity to redesign living organisms, the products of some three billion years of evolution… It presents probably the largest ethical problem that science has ever had to face. Our morality up to now has been to go head without restriction to learn all that we can about nature. Restructuring nature was not part of the bargain…for going ahead in this direction may be not only unwise but also dangerous. Potentially, it could breed new animal and plant diseases, new sources of cancer, novel epidemics.

On the other hand, in an article "Viewpoint: All for the Good-Why Genetic Engineering Must Soldier On", James D.Watson in 1999 stated:

> The double-helical structure of DNA, initially admired for the intellectual simplicity, today represents to many a double-edged sword that can be used for evil as well as good…Never postpone experiments that have clearly defined further benefits for fear of dangers that can't be quantified. Though at first it may sound uncaring, we can react rationally only to real (as opposed to hypothetical) risks. Yet for several years, we postponed important experiments on the genetic basis of cancer, for example, because we took much too seriously spurious arguments that the genes at the root of human cancer might themselves be dangerous to work with.

IV. Conclusion

Gene research has caused changes in medicine and life style. Even economics, politics, ecology, ethics and society are greatly affected. Mankind could definitely appreciate the technology for helping cure certain diseases. We do not have to be scared because of the ignorance. Yet the limitations should be cautiously considered. The natural world may be completely made over someday. Here I urge that we become genetically literate in order to make our own informed choice. We can start a working group with members

from fields of medicine, sociology, anthropology, law, education, health policy, genetics, psychology, biomedical ethics and philosophy. With genetic engineering, science has shifted from exploring the natural world to redesigning the world. The ethical and theological implications that genetic revolution brings are thought provoking.

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