Ethical Issues in Genetic Engineering: A Survey

by Thomas A. Shannon

Introduction

Of all the developments in science, medicine and engineering in recent decades, perhaps none has captured the imagination as much as genetic engineering. In one way this is surprising because genetics is not easily understandable, particularly given the complexity of the genetic code.

But in another way the fascination is understandable. For even with minimal understanding of genetics, we can sense the attraction of engineering the engineer. That is, we have the capacity to influence directly the basic units of inheritance and thus shape not only the lives of specific human beings but also the course of evolution itself.

Our imaginations have been captured by literary and film portrayals of the applications of genetic engineering. Novels such as Huxley's *Brave New World* and Robin Cook's *Mutation* present the dark side of genetic engineering with frightening social and political implications. The film *Blade Runner* presents genetically engineered warriors going out of control, as well as an interesting relationship between a human being and a genetically engineered entity. A movie from several years ago, *The Boys From Brazil*, presents an attempt to replicate other Hitlers by cloning and replicating the major developmental events of Hitler's childhood and adolescence.

Since the DNA molecule was first described by Watson and Crick in 1953, researchers have steadily advanced our understanding of human genetics. As a means of coordinating this investigation, scientists have organized the Human Genome Project, one of the largest research programs of the century. Its purpose is to map the entire human genome. This paper will explore some ethical and social implications of emerging genetic technologies.

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Genetic Engineering: The Ethical Issues

Motive

Apart from satisfying the seemingly innate curiosity we have about everything in our world, why would we want to study genetics and engage in genetic engineering?

First of all, knowing what information is transmitted genetically will help us identify the cause and mechanism of many diseases that are passed from parent to child. Knowledge about the causes, location and operation of these genetic transmitters will give us the capacity to intervene and replace the faulty gene with a correct working model.

Here the motive of genetic engineering is the traditional medical motive of providing therapy for one who is or may be ill. The difference, and it is a critical one, is that the disease wil[l] be prevented from occurring because the gene which causes it will be replaced with a correct copy. Such a possibility would be [a] blessing for those who are carriers for a particular disease, sickle cell anemia or Huntington's chorea, fo[r] example, but would like to have children. This therapeutic motive for genetic engineering, stands wel[l] within the traditional ethic of medicine and presents the same or similar ethical issues involved in the customary practice of medicin[e].

A second motive is to use variou[s] genetic technologies or interventions to enhance a particular trait o[r] characteristic. A commonplace example, but quite profound both socially and economically, is the commercial use of selective breeding techniques to produce chickens with enhanced body parts but which also require less feed to attain their size and can reach market quicker with a better profit margin.

On a different level, animal breeders are cloning several identical copies of animals from a single embryo. In this technology, the genetic material in the unfertilized eggs of a donor cow is removed and replaced with genetic material from a prize cow. These eggs are then frozen for later use or are fertilized with semen from prize bulls, implanted into surrogates who then give birth to genetically identical calves. Thus the desired traits are more quickly produced and brought to market.

Routine genetic screening raises concerns about personal integrity and privacy. Is it legitimate to use a clinical test to ascertain information that is almost exclusively social?

Transgenic animals are also becoming a staple of the laboratory and farm. A transgenic animal is one who has genetic information from another species inserted into it. A successful example has been the development of mice whose milk produces an agent used to prevent heart attacks in humans. Cows have been given a genetically engineered enzyme to enhance their milk production. And, in the opposite direction, a mouse has been engineered to make it susceptible to cancer so it can be used for research.

Here the intent is to enhance a particular capacity or characteristic of the entity in question. And it is here that many of our most difficult ethical and social questions arise. Some have asked whether it is appropriate to use animals in this way. This question is sharpened in light of the possible upset of the ecological balance and the impact on evolutionary development. Another question is whether it is possible for humans to own patents on animals, particularly when that animal has a capacity not found in nature and which was put there by researchers or institutions seeking such a patent. While the legal dimension of this question has been answered affirmatively in the United States, the ethical dimension is being reviewed from the perspective of the developing animal rights movement. Considerable rethinking of this issue is going on at present.

But more urgent questions concern the application of these technologies to humans beings. One example is the use of genetically engineered human growth hormone. Originally developed to correct dwarfism, the hormone is now available for children with "short child syndrome," that is, normal children who are of average or less than average height. Since we know that taller people command greater respect and higher salaries, it is not surprising that many parents want to ensure the advantage of height for their children. But short stature is not an illness, thus on what medical grounds might a physician legitimately prescribe it?

Another example is Dr. Robert Graham and his Repository for Germinal Choice. Having made a fortune by inventing safety glasses, Dr. Graham was motivated to help society by increasing the number of highly intelligent people in the expectation that they would become scientists. To do this, he asked Nobel Prize winners to donate their sperm so it could be used in artificial insemination. Dr. Graham neglected the genetic contribution by the woman and the fact that it was the parents of the prize winners who contributed the genetic information. He also incorrectly assumed that there is a single gene responsible for intelligence.

As we develop the capacity to engineer the engineer, we need to keep in mind what we are trying to achieve and ask why that is a good idea.

Prenatal Diagnosis

Another common application of genetic knowledge is the routine screening of pregnancies by amniocentesis, chorionic villi sampling, ultrasound or fetoscopy. In the first two techniques fetal cells are obtained, cultured and then examined for genetic anomalies. In the last two procedures the embryo or fetus is observed either indirectly via a monitor or directly with the use of fiber optic cables. These technologies help us observe developmental progress and discover various anomalies.

Who should own or control genetic information? Is the genome map public property or will it be patented and available only for a fee?

While several thousand genetic diseases can be diagnosed in this fashion, the tragedy is that the vast majority cannot be cured. Occasionally an intervention can be made, such as a blood transfusion or immediately initiating a particular diet, but in the majority of cases we only gain knowledge from the diagnosis. Occasionally an anomaly is discovered whose effect is not known. Here the parents will be in a position of knowing there is a genetic variation but not knowing what effects, if any, might follow from it.

Another dimension of genetic screening is learning the sex of the embryo. Such knowledge is medically relevant if, for example, the embryo is at risk for a sex-linked disease such as hemophilia. But suppose, as is sometimes the case, that the individual or couple wants to know the sex because they have a birth order preference for their children? Polls show that most individuals, including women, prefer sons as the firstborn. Acting on such knowledge could significantly skew population distributions, would confer additional social advantages on males, and would introduce sexual discrimination into the birth process. One needs to ask whether it is legitimate to use a medical test to ascertain information that is almost exclusively social in nature.

While genetic screening has its place, particularly if a couple who are not obvious carriers of a genetic disease have an affected child, or if either or both partners is a carrier, there are several important ethical issues. First, there is a "guilty until proven innocent" assumption operating here. That is, the fetus is suspected of having a genetic disease until proven otherwise. Since only about three percent of fetuses so screened are shown to have anomalies, one wonders about the legitimacy of such an assumption and why screening is so prevalent.

Screening assumes that those without genetic anomalies will incur lower health care costs or utilize fewer of the community's resources. While it is true that individuals with genetic illnesses do incur health care costs, it is also true that so does almost everyone else. And the assumption that such causes are primarily genetic ignores the fact that many illnesses are caused by environmental pollution as well as by personal choice. For example, the practice of smoking is not caused genetically, but it accounts for a tremendous health care expense annually—as does drug addiction and drunk driving.

Will the knowledge we learn about ourselves lead to a "genetic fatalism" which says that because we have a given genetic configuration we are destined to live or act in a certain way?

Finally, information about the genetic status of the fetus is typically gained late in pregnancy, usually after the 15th week. The problem is that the woman or couple are emotionally invested in the pregnancy by now, typically a pregnancy of choice or one that was achieved only after great difficulty. A significant amount of tension is introduced into the pregnancy by the assumption that there may be an anomaly, by the two or three week waiting period for the test results, and the difficulty of what decision to make should there be a genetic error. All of this contributes to a new form of pregnancy that Barbara Katz Rothman calls the "tentative pregnancy."

When indications call for it, prenatal diagnosis can be a helpful way of diagnosing problems. But we need to think carefully about the personal and social implications of routine screening.

The Human Genome Project

The first serious discussions of providing a map of the human genome began in the late 1980s and led rather rapidly to the funding of a project to implement the idea. Several factors drive this project. One is the basic curiosity we have about ourselves: who are we, what makes us up, why we act the way we do, and how we learn, remember and experience? Scientists hope that a fuller understanding of the genome will supply insight into these basic questions. Clinical investigators seek specific medical gains. Once one learns where a particular gene is and what it does, one can then intervene to correct a malfunctioning gene. This would open the possibility of therapeutic intervention for many of our most serious diseases. By knowing an individual's genetic structure, one might also be able to make predictions about future health or vulnerability to particular illnesses. Thus the genome map offers significant opportunities for gains in knowledge and therapeutic intervention.

But, as in all other areas of life, these opportunities come with the equally strong possibility of high costs. For example, on the scientific level, commitment to the genome project means that many other scientific projects will not be funded. This reality is causing heated debate among scientists who see many worthy prospects being put on hold for several decades.

Several other thematic issues arise from the genome project. The question of control or ownership of information is critical. Is the map of the genome public property, accessible to any scientist who wants particular genetic information for his or her research? Or will this map be patented and available only for a fee? Will it be the property of the government or of the scientists, laboratories or universities at which the work was done? These issues have not been fully studied, much less resolved.

Who will have access to this information? Obviously, full genetic information about individuals would be of interest to insurance companies or employers who provide health care benefits. But is the knowledge of one's genetic makeup included in the right to privacy?

Will the knowledge we learn about ourselves open the way to a "genetic fatalism" in which we assume that because we have a certain genetic configuration we are destined to live or act in a certain way? Will we assume that learning an individual's genetic composition gives the key insight into him or her, and thereby neglect the environment in which he or she lives or the nurturing he or she receives? Could genetic profiles lead to a social ranking of individuals?

It is clear that some diseases are caused by genes that malfunction or are damaged and that short of replacing the defective gene with a working copy, there is little one can do to prevent the disease from occurring. But is this the model for all human activities or behavior? Again, such issues are not resolved and we would do well to examine carefully claims that all behavior can be traced to specific genes.

Conclusion

This paper has reviewed a few important developments in genetics. Some of these are older in that the technologies have been with us for several decades, whereas others are newer and are a consequence of recent advances. Yet all of these techniques, plus the knowledge they generate, significantly challenge our assumptions about human nature, our values and our understanding of society.

The genetic revolution assumes (as does much of our culture) that information and knowledge will resolve many of our problems, either individual and social. That is, once we have a map of an individual's genetic structure we will know much about his future. We will have a privileged insight into his potential and abilities. We will know what makes him tick.

But will we? While it is clear that our genes are responsible for much of our behavior and our physical dimension, it is not clear that genetic structure provides a full or adequate account of human behavior. While research continues, and it should, we need to be constantly on guard about simplistic explanations of complex behavior.

The genetic revolution assumes that once we have a map of a person's genetic structure, we will know what makes him tick. But will we? It is not clear that genetic data will provide a full or adequate explanation of human behavior.

Many of the discussions about genetic engineering, particularly those in either literary or film science fiction, reveal interesting value dimensions. Most of these works present images of genetically engineered warriors or slaves. The values emphasized range from power, intelligence, strength to docility and obedience. Seldom does one find portrayals of gentleness, kindness, compassion, tenderness, creativity or concern for others. When one reads discussions of what traits to select or which characteristics to enhance, these are definitely not the ones mentioned! What does that say about us both individually and as a society? What does it say about our priorities?

The most important debate in genetics may not be about which project to fund or which technique to implement, though these are surely pivotal. Rather, the most critical debates highlight the values on which we base our decisions and the priorities we are trying to actualize in our society.

The creation account in the book of Genesis tells us that we are created in the image of God. The rapidly developing capacities of genetic engineering will give us the power to create our descendants in another image. Whose image will that be, and what values will it embody? Such is the individual and social debate before us as we enter a new age of genetic discovery. ♦