

Implications of Genetic Discrimination: Who Should Know What?

Imagine a picture of yourself in 20 years. Where would you be? What would you be doing? Who would be standing beside you? Many people believe that their genes provide an analogous picture of their medical future. This belief is not only wrong, but dangerous.

Advances in the human genome project have revealed ways to obtain knowledge of an individual's present medical condition and future risks, but do not allow an exact prediction of the individual's medical future. A physiological defect is not always governed by a person's genes and, most of the time, the presence of certain alleles serves only to confirm a greater risk of developing the corresponding disease. In only a few cases, research in human genetics has made it possible to clearly link genetic makeup to an unavoidable disease. These specific cases, which are far fewer than perceived by the public, raise issues of genetic discrimination. They also serve as a warning that future research will progressively reveal more disease-gene links, thus leading to an urgent need for thoughtful examination of the issues, policy making, and guidelines for minimizing the dangers of genetic discrimination based on access to genetic information. This paper outlines first, the risks of unrestricted access to genetic information, then the advantages of access to genetic information, and finally proposed actions to control genetic discrimination.

Risks of unrestricted access to genetic information

One major risk of unrestricted access to genetic information is discrimination by health insurance companies. This risk is specific to the United States, due to its privatized health care system. As the U.S. health care system becomes more socialized, the risks of genetic discrimination by health insurance companies will be reduced. Whereas insurers previously used group statistics to determine risks of diseases, they could obtain more reliable information on the likelihood of developing a disease based on individual genetic information. Armed with an individual's genetic information, insurance companies could identify and quantify that individual's risk factors and adjust his premiums accordingly. In order to increase profit per patient, the insurers could set up individualized premiums based on each patient's risk level, so that instead of having equal premiums based on shared risk, people whose genetic make-ups demonstrate greater risk would have higher premiums. Taken to the extreme, those whose genetic information predicts diseases that require extended or extremely expensive treatment could find their premiums prohibitively expensive or be denied coverage altogether, even though these are the people who most need medical insurance.

Medical insurance is provided by employers for three-quarters of the American population. Twelve out of the Fortune 500 companies are already doing genetic screening during the employment process. This offers the company a chance to reduce medical insurance premium costs for their employees. In this way, genetic discrimination can be the basis of saving money allocated towards medical insurance premiums and increasing profit. More ominous, however, is the potential for employers' genetic discrimination based on predictions of productivity and time of death of employees. Why

hire, train, or promote an employee who is likely to become medically disabled five years sooner than others?

For example, Huntington disease is a neurological disorder that can be detected genetically before or after diagnosis. On the end of a short arm on chromosome 4, there are normally 10-20 repeats of cytosine, adenine and guanine (CAG). When 36 or more repeats of CAG are detected in this location, the patient has or will have Huntington disease. Because there is no treatment for this disease, death usually occurs after 15 years of progressive decline. A person predisposed to Huntington disease will have lower productivity and will probably die sooner than his peers. Given this information, an employer seeking a reliable, long-term employee would most likely discriminate against someone with Huntington disease, thus interfering with the afflicted person's equal opportunity. Given the expense of increased insurance premiums, most employers would avoid hiring that person, leaving him unemployable long before his abilities have been affected by any medical condition.

In addition to risks involved with medical insurance and employment, there are many personal decisions which could be influenced by unrestricted access to genetic information. If colleges, medical, law or business schools had access to the genetic makeup of their applicants, they could find out which ones were predisposed to diseases that would lead to early death or low productivity. The consequence could be less recognition or financial contributions for the school and therefore, the admissions department might be less inclined to offer admission to an applicant based on genetic information. Another scenario of genetic discrimination is in the case of adoptive parents and egg or sperm donors. Genetic information given to adoption agencies, sperm banks,

and people requesting egg donations could lead to discrimination as prospective parents attempt to bring genetically privileged babies into their lives. Even marital decisions could be affected upon learning about a partner's genetic information. Computer-assisted matching services are becoming popular, especially among young adults with demanding careers, so supplementing the available data with personal genetic information is foreseeable in the near future. Such examples of the possible uses of genetic information are countless, and so are the risks of genetic discrimination.

Advantages of access to genetic information

The primary advantage to open knowledge of one's genetic makeup is a more individualized, effective and efficient medical treatment. A patient's genetic information provides his doctor a more complete background of his condition. With this knowledge, the doctor is able to prescribe more appropriate, more effective treatment, including medications. With further progress in genetic research, doctors may soon be able to identify genes that would predispose negative or positive reactions to certain drugs, and side effects to others. This knowledge would help patients avoid having to try several different drugs or treatments to find the one that effectively treats a disease and eliminates or minimizes deleterious side effects. Thus, the treatment process would become more clinically and cost effective, and the patients would save money, time and effort, and experience less unnecessary suffering.

An extreme example of a situation in which an appropriate drug choice could be based upon genetic testing involves the effect of gas anesthetics on only one in 20,000 people. When routine gas anesthetics are administered to these patients, their muscles

immediately become rigid, they develop a high fever, hyperventilation and an irregular heartbeat. These side effects of the gas anesthetics can only be stopped by the immediate administration of corrective drugs. The only detectable sign to identify these patients beforehand is the defective gene that codes for calcium gates in muscle cells.

Another possible advantage to a doctor having access to his patients' genetic information is the prospect of delaying or even preventing the onset of a disease. For example, phenylketonuria (PKU) is a genetic disorder that affects approximately one in 10,000 births. It is caused by the incapability of metabolizing phenylalanine, one of the twenty essential amino acids. As a result, phenylalanine builds up and causes mental retardation. Tests on newborns that reveal this inability to digest phenylalanine, and can help minimize mental retardation when parents are encouraged to give their children a diet low in phenylalanine. These tests are already required in the United States for all newborns. The scenarios for other incurable, but treatable diseases such as cystic fibrosis, sickle-cell anemia, and beta thalassemia are similar in that people with these diseases may be afforded the opportunity to improve their quality of life and even prolong their life with the early availability of certain genetic information.

Another important advantage to having access to genetic information is personal safety. Some people have genetic variations that cause them to be more susceptible to certain problems, conditions, or chemicals. People with these variations would need to exercise caution when choosing a workplace or a home that expose them to these potentially dangerous conditions or chemicals.

Lastly, there is a clear advantage to access to genetic information when it promotes the safety of society. In this area, employment discrimination based on genetic

information could work to the advantage of a large number of people. An example of a large group benefit from access to genetic information is the case of Huntington disease. This disease leads to the loss of motor control.

People with the Huntington disease allele should arguably either not be allowed to have jobs in which a loss of motor control would put others in danger, or be required to have regular tests for motor control. Jobs that would endanger others in the case of loss of motor control include airplane pilot, air traffic controller, bus driver, etc. This situation is similar to that of epilepsy in that those affected by epilepsy are not currently allowed to have certain jobs. With future discoveries in human genetics, tests will include and identify people with other diseases which could endanger others. The safety of society is an imperative consideration when evaluating the implications of genetic discrimination.

Proposed action to control genetic information

In order to best use the new discoveries in human genetics without unfairly discriminating against people with genetic disorders, a clearer definition of genetic testing and a better understanding of the limitations of our current knowledge are needed. Education of the public, law makers, employers, and insurance companies is essential to take full advantage of what genetic information has to offer while protecting the potential victims from its misuse.

Better education about genetic information would lead to better policies about its use and misuse. We need well informed law makers to enact laws to establish proper use and prohibit improper use of genetic information. We need well-informed employers and

insurance companies to implement appropriate policies. We need a well-informed public to keep the pressure on the politicians, employers and insurance companies to act responsibly on these issues.

New laws are absolutely essential in order to protect people whose genes put them at risk for discrimination, whether rational or irrational discrimination. Legislation protecting the public from improper use of genetic information would also serve to reduce the public's fears about genetic information in general, which would reduce the threats to cut off genetic research.

Policies dealing with genetic privacy must be made before the genetic information is distributed, since it would be difficult, if not impossible, to take back that information and undo the damage it could cause. There is a need to examine, debate, and resolve these issues before the decisions are required by advances in medical knowledge, so that reasoned choices are made about limiting access to genetic information. This requires the legal and political worlds to anticipate the problems that advances in genetic research will raise, which reinforces the need for education of the law-makers in the area of human genetics.

Both the effort to educate and the effort to create responsible policies will inspire more support for continuing genetic research. A public equipped with a better understanding of genetic research will have fewer fears of the perceived problems it now associates with this research. The current fears are based on greatly exaggerated dangers of using individual genetic information. Biotechnology firms, researchers hype up the importance of genetic information in order to win support for their work. Advocates for genetic privacy overemphasize the dangers of genetic information in order to scare the

public away from allowing access to genetic information. The media focuses on the scariest aspects to gain audience interest. The effect is that the public is frightened of genetic research itself, specifically of how insurance companies and employers could misuse genetic information. Their fears are not unjustified, but could better be applied to insisting on the responsible control of access to genetic information.

Another factor that plays into the fear of genetic research is the increased extent to which people see their lives as dictated by their genes. This feeling of loss of control of one's future could reduce the sense of responsibility for one's actions and therefore one's life course. A potentially dangerous example is the situation that would be created if an alcoholism gene were found. If a person is told upon a genetic test that he had the gene that predisposed him or could result in alcoholism, he might give up trying not to drink and would blame his problems with alcohol on his genes instead of his choice to drink. These perceived fears of genetic research can also be eliminated by education. More research will lead to more precise knowledge and the ability to treat, prevent, or cure genetic diseases.

Conclusion

Advances in human genetic research are giving us the tools to detect, treat, and even cure many genetic diseases. Modern medicine is in the middle of a revolution thanks to the field of human genetics. We can only dream of what seemingly medical miracles this research will one day allow us to carry out. In addition to the excitement of the discoveries on the genetic front, we must anticipate the risks and problems that will inevitably follow the availability of new genetic findings. Laws must be drafted and made with the goal of protecting those who could potentially be endangered by the

abilities gained from genetic research. These laws are essential and are needed now, before genetic information is distributed to inappropriate recipients, before individuals suffer unnecessary genetic discrimination, and before fears can totally cut off genetic research.

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