Impact of Genetic Discrimination

The recent sequencing of the Human Genome Project has brought about the ability to identify genetic markers for a wide-variety of genetic diseases and health conditions, such as Alzheimer's disease, Huntington's disease, breast cancer, hemochromatosis, and cystic fibrosis, just to name a few. Doctors can often determine whether a patient is at risk of developing a potentially devastating disease merely by looking at her genes. However, along with the advantages of being able to identify this genetic information in order to take precautions, treat the disease, or plan a family, come issues regarding the effect of the genetic testing on the self-image of the individual tested. Also important to consider are the implications that genetic testing has on privacy and informed consent, as well as the effect on the willingness of individuals to partake in genetic testing for personal knowledge or biomedical research at the risk of finding out sensitive personal genetic information and/or having that information made available to third parties.

While the rapid advances in genetic technologies undoubtedly offer great promise for the diagnosis and treatment of inheritable diseases, they also raise serious concerns about the potential for the use of this genetic information to discriminate against certain individuals. Two key areas where there are evident problems with genetic discrimination are insurance and employment. People who today are healthy may find themselves without health care coverage or even a job because a mutation identified in their genes indicates a statistically higher chance that they will be stricken with a specific disease later in life. Discrimination resulting from this genetic information occurs perhaps years before the person exhibits symptoms of the disease, if the disease even manifests at all.

In the U.S., the Food and Drug Administration has declined to regulate genetic tests, and the results of such tests are currently made available to insurers and employers, among others. No other government entity regulates genetic tests in the U.S., so no federal oversight or quality control mechanisms are in place to monitor the accuracy and reliability of the tests or the laboratories that process them. A study of 245 molecular genetic testing labs found that 36 labs (5%) scored lower than 70% on a quality-control scale.[1] The researchers conducting the study pointed out the need for improved personnel qualifications and laboratory practice standards. Because of the lack of standards to regulate genetic testing, decisions based on genetic testing results may not only be based on flawed ethics, but flawed test results.

Genetic testing generates unique medical information because of its ability to indicate that currently healthy people may develop a devastating disease in the future. Medical information is generally required by law to be kept confidential, in part to encourage people to seek medical treatment, even if doing so requires them to disclose information that they feel is embarrassing or stigmatizing. But, as with all medical information, the confidential maintenance of genetic information depends upon the nondisclosure and privacy safeguards of those with access to the information, including medical personnel.

The irony of genetic testing is that, even in rare cases where a treatment exists, people may be afraid to get tested for the disorder because it might lead their insurer to drop them entirely or cause an employer to refuse to hire them. Hemochromatosis is a chronic, fatal disease in which too much iron builds up in the blood that can easily be treated by periodic withdrawals of blood. A graduate student recently chose not to be genetically tested for hemochromatosis even though both his father and uncle had the disease because he was worried about his job prospects.[2] In another case, a man who was tested for hemochromatosis and successfully treated

found that his insurer cancelled his health policy on the grounds that he might stop undergoing treatment.

The disclosure of genetic information to parties outside the immediate treatment context increases the risk of discrimination. Insurers, mortgage companies, schools, and other institutions may wish to make decisions about people based on their genetic profiles. For example, employers may rely on genetic information to deny someone a job or promotion because that individual's genes suggest that the individual (or a family member) has a statistically higher chance of becoming ill. In the employer's mind, it might not be worth training an individual who the employer feels will "just become sick" later on and quit. Also, the employer may discriminate against the applicant in order to avoid the monetary costs associated with absenteeism, reduced productivity, or increased medical claims. The employer does not *know* that the individual will become ill, but is instead relying on an assumption that the person will become sick later on. The applicant may *never* become ill, though, and may perform better in the job than other applicants, even in the event of illness. This genetic discrimination also fails to take into account non-genetic factors that may have a greater impact on illness-related absenteeism than any genetically-linked illnesses have.

Courts have already faced questions of whether genetic information is being improperly collected or improperly used in the employment setting. For example, in *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998), former and present employees of Lawrence Berkeley Laboratory alleged that it improperly tested their blood and urine for medical conditions without their knowledge or consent. Allegedly, the lab used blood from employee physicals to secretly test African-American employees for sickle cell anemia and female employees for pregnancy. Judge Reinhardt of the Ninth Circuit Court of Appeals stated: "One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic makeup." The Court ultimately found that such tests could be considered a violation of one's constitutional right to privacy and unconstitutional discrimination.

The Equal Employment Opportunity Commission (EEOC) has also received complaints about employers who use genetic testing. Several Burlington Northern employees complained to the EEOC that Burlington Northern required that any employees who claimed to have developed carpal tunnel syndrome undergo a genetic marker test. Some claimed that they did not consent to such testing, while others alleged that Burlington Northern retaliated against those who refused to submit to the genetic test. The EEOC argued that the policy clearly violated the Americans with Disabilities Act. Ultimately the matter was settled by Burlington Northern agreeing to pay $2.2 million to the employees and refraining from using genetic testing in the future.

Similar to the employment realm, genetic discrimination is also entering academia. When faced with applicants who have similar grades and experience, schools may use genetics as the "tie breaker," admitting those whose genes suggest that they have a statistically higher chance of avoiding genetic diseases. Already one medical school did not want to admit an applicant *at risk* for Huntington's disease (an untreatable devastating neurological disorder that is often fatal by age 50) on the grounds that it was not worth training someone who would have a shortened practice life.[3] The school did not know if the applicant would, in fact, become ill or fail to make a substantial contribution to medical practice even in the event of illness, but the assumption was made that training the applicant was not worth the risk.

With respect to discrimination in insurance, there are large financial incentives for insurers to try to identify people who may need expensive health care in the future, and to use that

as a basis for rejecting applicants. Researchers from the National Institutes of Health estimate that more than 40% of the $1.2 trillion cost associated with brain and nervous system disorders (including depression, stroke, Parkinson's disease, Huntington's disease, schizophrenia, Alzheimer's disease, multiple sclerosis, migraines, and anxiety disorders) is related to genetic factors. Many of the genes associated with diseases or disorders that cost the most money to society are now detectable through genetic testing.

Insurance companies consistently use "underwriting standards" such as the applicant's age, height, weight and smoking habits, in deciding whether to cover applicants. As genetic testing becomes more common and in absence of national legislation barring genetic discrimination, one concern is that insurers will consider predispositional genetic information as part of their underwriting standards to determine premiums, terms, and conditions of coverage. Even where an insurer does not initially have or use genetic information in granting coverage, subsequent information acquired through the bills submitted to the company for reimbursement might then be used as a justification for cancellation or nonrenewal of the policy, increased premiums, or changes in coverage, including exclusions for treatment of the genetically-linked illnesses that the individual, family, or group has a higher probability of exhibiting. Indeed, in one instance, a newborn was diagnosed with PKU, a genetic disorder that can cause mental retardation if the infant is not treated soon after birth. The newborn, covered under her father's health insurance policy, successfully completed treatment for the disease and developed into a normal and healthy child. Her father then changed jobs when she was eight years old, and the family was told that she was ineligible for coverage under his new plan because of her previous diagnosis, despite the successful treatment of her condition.

Another case of genetic discrimination was brought by Terri Seargent in front of the U.S. Equal Employment Opportunity Commission under provisions of the Americans with Disabilities Act. After Seargent's brother died of a genetic disorder called Alpha-1 Antitrypsin Deficiency, she decided to submit to a blood test to examine her own disease-predicting mutations and variations. When Seargent tested positive for the genetic mutation associated with the disease that killed her brother, she immediately sought medical treatment to try to prevent the start of the disease. Seargent's employer, which was also her health insurer, allegedly used the results of the blood tests as a basis to fire her and withdraw her medical coverage. She then submitted a statement for the written record of the Senate Health, Education, Labor and Pension Committee on Thursday, July 20, 2000 for genetic discrimination in the workplace hearings.[4]

Even people who have voluntarily participated in genetics research have lost their health insurance as a result of it, including a man who underwent screening for APC (adenomatous polyposis colon cancer) as part of a research study.[5] In another case, a woman underwent genetic testing for a predisposition for breast cancer at a major medical facility in Chicago. She requested to pay for the test herself, in cash, in order to keep the test and its results from being reported to her health insurance company. Other individuals refuse to undergo genetic testing because the resulting information may be used against them. For example, June Walker, president of the Jewish women's organization Hadassah, said that Hadassah has been pursuing the fight against genetic discrimination since they discovered that there is a high frequency of genetic predispositions toward breast and ovarian cancers among Jewish women. Walker stated, "individuals are hesitant to submit to genetic tests for fear of insurance and employment discrimination."[6] For that reason, the Biotechnology Industry Organization, which represents companies and academic institutions engaged in biotechnology research, supports genetic antidiscrimination laws and practices because discrimination "may lead people to avoid obtaining information about their current or prospective health status."[7]

Beyond the individual, genetic information also has implications for an individual's family members. Huntington's disease, for example, is a dominant disorder where the children of at-risk individuals have a 50% chance of inheriting the disease. Huntington's disease is a genetically linked illness, striking in middle age and progressively destroying the brain's neurons. This retards one's motor skills and slowly causes confusion, irritability, depression, dementia, movement disorders, and death.[8] Genetic testing that indicates that an individual has the potential to develop Huntington's disease may cause genetic discrimination against his or her family as well because of the inheritable nature of disease.

The use of genetic information may extend well beyond one's immediate genetic relatives to include an entire community when an assumption is made (properly or improperly) regarding the sharing of particular traits or genetic conditions across the community or ethnic group. In this way, disclosure of one's genome may be used to make assumptions about others in one's group. For example, in 1998, Swiss drug manufacturer Roche Holding of Basel announced that it would pay $200 million for research conducted by deCode Genetics, a genetics firm based in Reykjavík, Iceland, because deCode Genetics has access to and has been conducting genetic testing on almost the entire Icelandic population.[9] This population is believed to be one of the most homogeneous populations in the world, and so it has been assumed that information about one Icelander's genome would be applicable to nearly the entire country's population.

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[1] Andrews, Lori, Future Perfect: Confronting Decisions About Genetics, (Columbia University Press: New York 2001).

[2] Bob Groves, "New Privacy Fight is All in the Genes," The Record (Bergen County, NJ), July 18, 1999, at N04.

[3] National Commission for Control of Huntington's Disease and its Consequences, Report Volume I: Overview DHEW Pub. No. (NIH) 78-1501 (1977).

[4] A copy of the statement that Terri Seargent submitted to the Senate Health, Education, Labor and Pension Committee on July 20, 2000, which more fully describes her story, is available at: http://www.alpha1.org/programs/newsmakers_seargent.htm, last visited September 16, 2004.

[5] Lori Andrews, "Body Science," 83 A.B.A. J. 44-49, 47 (April 1997).

[6] *See* "Medical Privacy Issues; Senate Bill Bans Some Use of Genetic Data," Genomics & Genetics Weekly, November 7, 2003, at 88.

[7] *See* BIO Policy Statement Regarding the Prohibition of Discriminatory Use of Medical Information Approved by BIO Board of Directors, March 1999, *available at:* http://www.bio.org/bioethics/privacy99.html (last visited July 23, 2004).

[8] At any given time, about 25,000 Americans are suffering from Huntington's disease but at the same time 150,000 others live knowing that they have a 50% chance of having inherited the gene and thus may develop the disease. *See* Peter Gorner, "Out of the Shadow A New Genetic Test Can Foretell Agonizing Death: Would You Take It?" Chicago Tribune, August 4, 1988, at C1.

[9] "DNA Research Raises Privacy Issues," American Health Line, December 7, 1999.