35. Genetic Testing by Employers

Introduction

Over the next 15 years, under the auspices of the federal government's "human genome project", scientists will try to map in detail each of the human cell's estimated 100,000 genes.[1] The knowledge derived from the project will enable physicians to detect an increasing number of diseases and predispositions for disease. It is expected that researchers will identify genes that contribute to the development of Alzheimer's disease, alcoholism, coronary artery disease, the different cancers and virtually every other illness.[2] In addition to enhancing the ability of physicians to diagnose disease, the knowledge from the genome project will result in better preventive and therapeutic measures.

Potential applications of information gained from the human genome project extend well beyond the setting of medical care. Employers, insurers and law enforcement agencies all will have uses for genetic testing techniques. In many cases, these uses will provide important social benefits. DNA fingerprinting can establish with greater certainty the identity of a criminal; it can also exonerate the innocent defendant. However, our past experiences with genetic and other medical testing suggest that abuses may occur. Some companies may have restricted employment opportunities of individuals who carry the sickle cell trait[3] even though there was no scientific basis for the restrictions.[4] In addition, employment discrimination has occurred repeatedly against individuals because of their medical problems. Previously, irrational fears led employers to deny jobs to patients with cancer or epilepsy.[5] Individuals with HIV infection continue to be victims of employment discrimination.[6]

In this report, the Council will address the use of genetic testing by employers to identify employees (or potential employees) who are at risk for developing certain diseases. Genetic testing by employers will involve the participation of physicians. This report will propose guidelines to help physicians assess when their participation in genetic testing by employers is appropriate and does not result in unwarranted discrimination against individuals with genetic abnormalities. The Council's guidelines are summarized in an opinion at the conclusion of the report.

Workplace Testing

Employers will have a number of potential justifications for genetic testing in the workplace. In some cases, there may be an argument in favor of testing for public health reasons. Companies have expressed concern about the possibility of an employee's genetic susceptibility to illness from exposure to a chemical or other substance in the workplace. In addition, employers may not want to hire individuals with certain genetic risks for jobs that bear on the public's safety. Other justifications are based not on concerns about health but on concerns about costs, specifically the costs to the *company* of hiring workers with a genetic risk of disease. Individuals who have a heightened risk for certain illnesses may be less attractive as employees; on average, they may be able to spend fewer years in the work force, and they may impose greater health care costs on the employer.

Since the acceptability of genetic testing turns on the purposes for which the testing is proposed, each of the proposed justifications for testing will be considered separately.

1. Future Unemployability. Employers may be reluctant to hire individuals who have a genetic predisposition for developing a disabling illness like cancer or coronary artery disease because these individuals may become prematurely unable to work. By excluding those at risk for becoming unable to

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work, employers may be able to lower their costs of recruitment and training.

As an ethical matter, however, future unemployability is not an adequate basis for performing genetic tests. Genetic tests are poor predictors of disease and even poorer predictors of disabling disease. Genes are often characterized by "incomplete penetrance"; that is, many individuals who carry the gene will never show manifestations of the gene. When the gene becomes manifest, it will be characterized by "variable expression" - the extent of the gene's effects may differ widely from person to person. Among individuals with sickle cell anemia, some die within the first years of life while others survive into their 50s.[7] In many cases, behavioral modification can limit gene expression. Patients at risk for diabetes can modify their diet, as can patients at risk for coronary artery disease. Even in cases in which the gene will ultimately cause a disabling disease, the effects of the gene may not appear for some time. For example, the onset of Huntington's disease does not occur until the patient is between the ages of 30 and 50 years.[8(p.163)] Consequently, the use of genetic tests would result in individuals being denied employment well before they became unable to work. In sum, genetic tests would have a high false positive rate and therefore result in many individu- als being denied employment unfairly.

Exclusion on the basis of future unemployability is problematic also because it can seriously undermine the principle that underlies the protection of disabled individuals from employment discrimination: disabled individuals should not be denied employment when their disability does not interfere with their ability to perform a job. If individuals could be denied jobs because of future inability to perform, then anyone with an HIV infection could be denied employment as could individuals with other diseases that lead to premature loss of the ability to function in the workplace.

Legal rules are in accordance with this ethical analysis. When construing statutes that forbid employment discrimination against the disabled, courts have consistently rejected an employer's argument that it should be able to deny employment to applicants whose future work might be compromised by health problems.[9,10(pp.124.126)] While these statutes do not apply to a large percentage of the workforce, the recently enacted Americans with Disabilities Act will prohibit virtually all employers with 15 or more employees from discriminating on the basis of disability.[8(p.114)] Under the Disabilities Act, medical testing will not be allowed unless the testing is related to the applicant's actual ability to perform the job.[11]

Employers should not be forbidden entirely from considering a person's future qualifications for a job, and the Disabilities Act will probably permit some consideration of future employability. An individual who would not be able to continue employment for more than a very short period of time, whether for health or other reasons, need not be treated the same as someone who can work on a long-term basis.[12] Important factors in assessing future employability are the likelihood that the employee would no longer be able to work and the length of time before the ability to work would be lost. However, employers can make valid distinctions on the basis of an individual's health status without using genetic tests. People who will become unable to work in a short period of time can be identified by medical testing that measures the effects of genes rather than the genes themselves.

2. Increased Health Care Costs. Employers may not want to hire individuals with a predisposition for cancer, Alzheimer's disease or other illnesses because these individuals might impose higher health care costs on the employer.

Many of the considerations that counsel against genetic testing to assess future employability apply here as well. Because of incomplete penetrance, variable expression and delayed manifestation, genetic tests have poor predictive value also when used as a method for limiting health care costs. In addition, protection against discrimination on the basis of disability would be vitiated if health care costs could be used as a criterion of employment. Individuals with disabilities typically have higher than average health care bills. Consequently, the Americans with Disabilities Act does not recognize higher health care costs

as a basis for screening potential employees.[9] The Act does permit employers to take health risks into account when issuing employee health and other insurance.[13] However, the Act expressly prohibits employers from using risk underwriting for insurance as a subterfuge to evade the anti-discrimination purposes of the Act.[13]

From the perspective of society's economic interests, denying employment on the basis of higher health care costs rarely makes sense. Whether or not the person with a genetic abnormality is employed, society will face the same health care costs. (An important exception would occur when a person .has a genetic susceptibility to injury from exposure to a chemical in the workplace, a situation that is discussed separately below.) If the person is denied employment, however, there can be no countervailing benefit from the person's ability to contribute productively in the workforce. Thus, if the disabled are working, society's economic interests are better served, as are principles of equity and justice.

There also would not be any unfairness to employers. Since all employers would have the same ethical obligations, any increases in costs would apply across the board. However, if some employers end up with a disproportionate burden of health care costs, it would be appropriate for the government to assist in the form of high risk insurance pools, tax credits or other subsidies.

3. Public Safety. In some cases, employers may want to use genetic tests to protect the public's safety. For example, employers of physicians or airline pilots may want to test for the gene that contributes to the development of Alzheimer's disease when such a test exists.

While ensuring the health of employees whose work bears on public safety is an important responsibility of employers, genetic testing is not an appropriate tool for meeting that responsibility. As when used for other purposes, genetic tests will have poor predictive value when used to identify workers who might pose risks to public safety. Incomplete penetrance, variable expression and delayed manifestation are problems here too. Thus, most individuals who would be excluded by genetic testing never would present a heightened safety risk. Anti-discrimination law has recognized that individuals might be wrongly denied jobs because of speculative safety risks. Consequently, employers must show that there is a significant or reasonable likelihood of harm to others from having a person with a genetic risk of disease employed before the person can be excluded from the workplace.[5(p.287),14]

Genetic tests are not only generally inaccurate when used for public safety purposes, they are also unnecessary. A more effective approach to protect the public's safety would be routine testing of a worker's actual capacity to function in a job that is safety sensitive. Airline captains, for example, currently undergo physical examinations every six months. Companies that employ bus drivers or ship operators have begun to use simple neurobehavioral testing on a frequent basis to test for impairment by drugs and other causes.[15] Routine functional testing could be used to detect those who become incapacitated by a genetic disease as the disease becomes manifest. In addition, the testing would detect those whose incapacity would not be detected by genetic tests, either because of a false negative test or because the incapacity was caused by something other than the disease being tested for.

Functional testing might also be required by the Americans with Disabilities Act. According to the Act, an individual cannot be excluded from the workplace on grounds of safety if "reasonable accommodations" by the employer would eliminate the safety risk.[14] If functional testing would be more precise than genetic testing at identifying workers who pose a safety risk, then functional testing would likely be viewed as a reasonable accommodation for the employer.[9]

4. Susceptibility to Workplace Exposures. Since at least the 1960s,[16] there has been interest in screening workers for genetic susceptibility to injury from chemicals or other substances in the workplace. Some occupational health experts have argued that genetic tests can be used to identify

workers who are particularly at risk for injury from workplace toxins.[17] In fact, black employees have been screened for the presence of sickle cell trait because of concern that exposure to nitro or amino compounds would result in sickling of the blood cells.[3(p.320)] Male workers have been screened for the sex-linked genetic abnormality of glucose-6-phosphate dehydrogenase (G6PD) deficiency because of concern that exposure to oxidizing chemicals would precipitate hemolytic anemia.[3(p.320)] Genetic screening has also been conducted to identify workers with $alpha_1$-antitrypsin deficiency on the ground that respiratory irritants might cause chronic obstructive lung disease.[3(p.321)]

While these genetic tests have been used to advise workers of potential risks and for research purposes, they also may have been used inappropriately to exclude affected individuals from the workplace. For instance, the apparent exclusion of workers with sickle cell trait [3(p.320)] was based on theoretical considerations that had no basis in fact.[4(P.372)] To date, there is insufficient evidence to justify the use of any existing test for genetic susceptibility as a basis for employment decisions.[18(p.1106)]

With greater understanding of genetic disease, researchers may develop tests that are more useful for identifying individuals at genetic risk for occupational injury. However, it is doubtful that a positive result on one of those tests will be a sufficient justification for denying employment to the affected person. The poor predictive value of genetic tests is relevant in this context as well. Many individuals with a positive test either will never express the gene, will express the gene mildly or will not express it for a long time. Consequently, many people would be denied employment unfairly.

There is also a serious concern with false negative tests. If companies adopt a policy of excluding "hypersusceptible" individuals from the workplace, they may relax their efforts to eliminate potential toxins from the workplace since the remaining workers will be able to tolerate a higher level of exposure to the toxins. However, because of testing inaccuracies, some affected individuals will not be detected. If they are hired, then they will face an especially elevated risk of injury.[19]

Protecting workers from occupational injury can be achieved much more effectively by offering workers the opportunity to be monitored both for their exposure to potential toxins and for adverse health effects from the toxins. When employees are exposed to lead, levels of lead in the workplace are regularly measured to prevent excessive exposures.[8(p.l06)] Similarly, in.workplaces where radioactivity is present, the amount of radioactivity that workers are exposed to is routinely monitored to ensure that the employees do not receive an inordinate dose. If workers develop too great an exposure to the toxin, then they should be transferred to a safer job without loss of salary, benefits, seniority, or opportunities for advancement. Under occupational safety and health law, when employees develop excessive blood lead levels from workplace exposure, the employer must provide an alternative job with existing pay and benefits for up to 18 months.[8(p.l06)]

In addition to offering routine monitoring, employers should notify applicants for employment of the occupational risks that they would face in the job and that genetic susceptibilities might increase their risk. The applicants could then have genetic testing performed by their own physicians and decide whether or not to assume the risk of exposure if the test is positive. Although there is insufficient justification for employers to exclude workers with genetic susceptibilities to injury, potential employees should be able to decide that they are unwilling to accept even a very small risk of injury.

It is conceivable that informing applicants and monitoring workers might not be adequate precautions. For instance, while there are no current examples, researchers may discover that a disease develops so rapidly that significant and irreversible injury would occur before monitoring could be effective in preventing the harm. In such a case, there may be a role for testing to identify those who are genetically susceptible to the disease so they can be excluded from the workplace.[20]

However, before genetic testing could be used for exclusionary purposes, other requirements would have to be met. The employer would have to demonstrate that the genetic tests are highly accurate, with sufficient sensitivity and specificity to minimize the risk of false negative or false positive results. In addition, there would have to be empirical data demonstrating that the genetic abnormality results in an unusually elevated susceptibility to occupational injury.

Employers would also have to show that it would be too costly to reduce the risk to the susceptible worker by lowering the level of the toxic substance in the workplace. In order to demonstrate undue cost, the employer would have to show that the costs of improving the safety at the workplace are extraordinary relative to other costs of production. Since the alternative to cleaning up the workplace is genetic testing and exclusion, the employer would also have to show that the costs of improving the safety at the workplace are extraordinary relative to the costs of testing potential employees for genetic susceptibility. These requirements would ensure that the costs of using the toxic substance are not placed on a few individuals but on society as a whole. Since society as a whole benefits from the use of the toxin, society as a whole should pay for its use.

Finally, genetic testing should not be performed without the informed consent of the employee or applicant for employment.

Under the Americans with Disabilities Act, if employers use genetic testing to exclude current workers from certain jobs, they may be obligated to offer them alternative employment.[21] Since genetic testing is ethically permissible only under very limited circumstances, the obligation to provide alternative employment would likely apply to only a small number of workers. Although the obligation does not apply to applicants for employment, .the Disabilities Act permits pre-employment genetic tests only in limited circumstances. While an employer may condition an offer of employment on the results of genetic testing that is job related, testing may not be performed until after a conditional offer of employment has been made.[22]

Evading the Prohibitions on Testing

Even if employers do not use genetic testing, they may still be able to discover whether their workers have certain genetic predispositions for disease.[23] Employers will often have access to the medical records of their employees. In some cases, medical records are obtained if there is a question of the employee's ability to resume work after an illness or accident. Although the employer would not need to receive the part of the medical record that includes genetic information, unnecessary information is often disclosed in response to a request for medical records. The patient's genetic information may also be disclosed if the patient receives treatment related to a genetic condition and files a claim for health insurance benefits. Measures will have to be developed to protect the confidentiality of a patient's genetic status.

For the reasons described in this report, the Council on Ethical and Judicial Affairs has developed the following opinion:

Opinion 2.131: Genetic Testing by Employers

As a result of the human genome project, physicians will be able to identify a greater number of genetic risks of disease. Among the potential uses of the tests that detect these risks will be screening of potential workers by employers. Employers may want to exclude workers with certain genetic risks from the workplace because these workers may become disabled prematurely, impose higher health care costs, or pose a risk to public safety. In addition, exposure to certain substances in the workplace may increase the likelihood that a disease will develop in the worker with a genetic risk for the disease.

1. It would generally be inappropriate to exclude workers with genetic risks of disease from the workplace because of their risk. Genetic tests alone do not have sufficient predictive value to be relied upon as a basis for excluding workers. Consequently, use of the tests would result in unfair discrimination against individuals who have positive test results. In addition, there are other ways for employers to serve their legitimate interests. Tests of a worker's actual capacity to meet the demands of the job can be used to ensure future employability and protect the public's safety. Routine monitoring of a worker's exposure can be used to protect workers who have a genetic susceptibility to injury from a substance in the workplace. In addition, employees should be advised of the risks of injury to which they are being exposed.

2. There may be a very limited role for genetic testing in the exclusion from the workplace of workers who have a genetic susceptibility to occupational illness. At a minimum, several conditions would have to be met:

a. The disease develops so rapidly that serious and irreversible illness would occur before monitoring of either the worker's exposure to the toxic substance or the worker's health status could be effective in preventing the harm.

b. The genetic testing is highly accurate with sufficient sensitivity and specificity to minimize the risk of false negative and false positive test results.

c. Empirical data demonstrate that the genetic abnormality results in an unusually elevated susceptibility to occupational illness.

d. It would require undue cost to protect susceptible employees by lowering the level of the toxic substance in the workplace. The costs of lowering the level of the substance must be extraordinary relative to the employer's other costs of making the product for which the toxic substance is used. Since genetic testing with exclusion of susceptible employees is an alternative to cleaning up the workplace. The costs of lowering the level of the substance must also be extraordinary relative to the costs of using genetic testing.

e. Testing must not be performed without the informed consent of the employee or applicant for employment.

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