

GENETIC TESTING: BLESSING OR CURSE?

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Genes are the sections of DNA that encode every ounce of a human's physical being. For years, humankind has strived to decode and fully understand these foundations of life, hoping that in them lay the answers to millions of unsolved mysteries: cures to diseases, causes of physical and psychological ailments, perhaps even a how-to-manual on redesigning genes. Yet, as we begin to reap the benefits of genetic knowledge, it often seems we are opening a Pandora's Box.

Since the launching of the Human Genome Project in 1990, it is becoming increasingly apparent that advancements such as genetic testing can be detrimental and act as instigators of discrimination. As genetic testing becomes more affordable, complex, and useful, genetic discrimination may soon become a widespread (and perhaps disastrous) reality. When privacy rights are broken as a result of genetic testing, people's health coverage, ability to acquire a job, as well as peace of mind may be affected.

Privacy has always been an issue in the medical world, especially since the shift to electronic health records. Such new measures for efficiency have taken away the choice of "selective recall," in which individuals decide what information will be given to health care providers.

Concurrently, genetic knowledge has been expanding in the past decade. Progress has been made in understanding complex, environmentally influenced, multiple-gene diseases such as cancer, diabetes, Alzheimer's disease, asthma, cardiovascular disease, and an innumerable more. The number of genetic tests available has also grown to beyond 1,500. In addition, Companies such as 23andMe, deCODE genetics, DNA Direct, and GeneDX are also offering marketing complete gene tests that may cost as little as one thousand dollars within a decade. The use of genetic information in even standard healthcare is becoming increasingly common. These recent developments have sparked reasonable concerns for genetic privacy.

To illustrate, in April 1999, a woman named Terri Sergeant tested positive for the alpha-1 antitrypsin gene, which is responsible for a disease that severely hinders breathing by stiffening the lungs. When her employer learned of her condition, which requires expensive treatment, she was fired and lost her health insurance. Cases like those of Sergeant reflect the main concerns regarding genetic testing. Individuals fear that knowledge of genetic predispositions can result in embarrassment, discredit, and financial difficulty that cancel out the benefits of genetic testing. Like in the case of Sergeant, insurers could deny health insurance or raise premiums for people with genes for costly disorders. Employers could also reject job-seekers or fire employees based on their genetic information. Individuals who have tested positive for harmful genes may also feel uneasy and stressed—lacking the peace of mind that a society should work to grant to all its members—when applying for jobs, compensation benefits, or obtaining life insurance, due to knowledge that their medical data can easily be used against them.

Awareness of such consequences can also act as a deterrent against genetic testing, which can be highly effective in preventing, treating, and curing lethal diseases for many people. Given the increasing rate of cancer, cardiovascular disease, and other conditions in these past few decades, more people are likely to have genes for these deadly diseases. Therefore, the number of people that would benefit from prevention and/or early treatment as a response to genetic testing is increasing. For people to neglect these opportunities due to fear of discrimination may severely endanger individual and public health, and waste the years of research that have gone into making medical breakthroughs in this field and preparing beneficial options for society.

In acknowledgement of the issues surrounding genetic testing, national and state governments have established laws hoping to protect individuals against discrimination and violations of privacy. However, existing laws against genetic discrimination are weak,

offering little protection for individuals in need of genetic testing. The two national laws regarding uses and disclosures of medical data, the 2003 Privacy Rule and the 1996 Health Insurance Portability and Accountability Act (HIPAA), both have significant loopholes, including issues relating to range of coverage (many large groups of people excluded), enforcement problems, severity of punishment (for 2003 Privacy Rule, only one monetary punishment was dealt), area of focus, and in short, ineffectiveness. Stronger laws, and perhaps changes to the national healthcare system, need to be made to account for the issues that will develop as genetic testing expands.

Genetic testing has significant health related benefits, but has introduced a new form of discrimination into society as well. As more people seek genetic testing for its potential to revolutionize treatment of many life-endangering diseases, and as cost decrease and availability increases, more cases of discrimination based on the precious information encoded in our double helixes are sure to arise. In essence, the advantages should outweigh the disadvantages—if the disadvantages are combated. More effective laws than those existing must be enacted. Genetic testing was meant to be a blessing, but what it becomes will depend on our next generation of scientists, policy makers, and voters.

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