

Genetic Discrimination and Insurance

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Final Project

Genetic Discoveries:

- Recent advances in genetics have included the discovery of genes related to disease.
- There has also been the development of tests for genes thought to be associated with certain disorders.
- These advances in technology has fostered the hope that healthy people will be able to predict future health by undergoing genetic testing, and possibly prevent future disease.

Implications of Genetic Testing for Insurance:

- Given the potential of genetic testing in predicting future health, many fear that insurance companies will misuse genetic information by raising rates or denying coverage to those who test positive for certain disorders or are known to be predisposed towards certain conditions, even if currently asymptomatic.

Negative Consequences of Genetic Discrimination:

- Genetic discrimination in health insurance could discourage individuals from seeking testing and prevent them from seeking timely treatment or making reproductive choices that could in the long run improve health and reduce healthcare costs for everyone.

Current Legislation:

- 1996 federal law, Health Insurance Portability and Accountability Act (HIPAA) prohibits health insurers from applying “preexisting condition” exclusions to genetic conditions that are indicated solely by genetic tests and not by actual symptoms.⁴
- Currently, 28 state have issued laws prohibiting insurance companies from using genetic information in issuing insurance or determining rates.⁹

Intended Purpose of Legislation:³

- Since fear of genetic discrimination is known to be a strong deterrent in individuals' decisions to obtain genetic testing, HIPAA and other laws restricting health insurers' use of genetic information is intended to:
 - (1) prevent unfair use of genetic information and
 - (2) to encourage more genetic testing for research, prevention, treatment, and family planning.

The Insurance Industry:

- Underwriting – a process where insurers determine the risk of an individual client and adjust their premium to acknowledge that risk.¹
- Medical underwriting for health insurance focuses on family history of disease and currently or previously existing conditions.⁴
- Life insurance also engages in the practice of risk classification in which clients are classified based on their expected mortality with the basis of risk being primarily age.⁸
- Struggle between actuarial fairness and social fairness.⁴

Complicated definitions:

- Genetic Tests – “the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect inherited disease-related genotypes, mutations, phenotypes, or karyotypes, for clinical purposes.”⁵
- There is no clear line between genetic and nongenetic tests.

More Complications...⁵

- Difficulty in determining what constitutes a genetic condition – some conditions, e.g. Tay-Sachs, have virtually purely genetic basis.
- Most genetic disorders involve an interaction between genetic predisposition and environmental factors.

And even more complications...

- Preexisting condition: What constitutes a preexisting condition?
- Predisposition: the potential for developing the disease is present, but the disease itself may or may not occur.
- Presymptomatic: the condition is already present but symptoms have not yet developed.

Current Situation:⁴

- There are few documented cases of genetic discrimination based solely on genetic information, even if the category is expanded to include family history cases.
- Regulators, independent agents, and reliable sources at insurance companies all said that genetic information is not used in underwriting for health insurance.
- None of the branches of the insurance industry – Blue Cross, HMOs, and commercial indemnity plans – inquire about genetic test results, use this information if found, or include genetic information in their underwriting guidelines.

Reasons for Current Lack of Discrimination:⁴

- Actuaries and underwriters say that proper medical underwriting focuses only on conditions that presently or previously existed, and “that it would be ethically wrong to penalize people for genetic defects that haven’t yet manifested.”
- Not economically beneficial to insurance companies.
- Health insurers use a short time-frame of reference in underwriting.

Potential for Discrimination:

Case study of hereditary breast and ovarian cancers:

- The presence of BRCA-1 gene suggests that 85% of women with this variant will develop breast cancer and 40% will develop ovarian cancer. This is in contrast to the lifetime risk of women without these genes, which is 12% for breast cancer and 1.5% for ovarian cancer.⁶

Benefits of Testing:⁶

- Testing for these genetic abnormalities is helpful since preventive measures could be started.
- Prophylactic surgery has been shown to greatly reduce the risk of cancer.
- Enhanced surveillance could lead to earlier detection of the cancer.
- Information could be used for making life decisions or family planning.

Implications for Insurance:⁴

- Genetic predisposition could predict current and future health care costs due to preventive treatment and increased monitoring.
- Could become a diagnosable disease category like high cholesterol and blood pressure, and “so be viewed as an existing condition” rather than presymptomatic.
- Reimbursement issues: changes classification of the disease.

Additional Reasons to Worry:⁶

- The quality of genetic testing will improve.
- Testing is easy compared with complicated family history questions.
- Financial incentives are present for both insurance companies and employers to use genetic information.
- Current anti-discrimination laws are untried and untested.

Loopholes:

- Current laws intended to prevent genetic discrimination have had little success in reducing patients' concerns about discrimination.³
- State legislation varies by state.⁹
- Self-funded insurance plans are governed by the federal Employee Retirement Security Act (ERISA) which preempts state laws and does not protect against insurance discrimination on the basis of genetic information.⁹
- The federal law, HIPAA, does offer some protection but does not prevent insurance companies from asking people to be tested or from asking for test results.⁹

Best Solution:

- Since genetic makeup is uncontrollable and not a voluntary behavior like smoking, no one should be “punished” with increased costs or limited access to healthcare.⁶
- Universal health care, based on the belief that health care is a basic right, would solve the problem since insurers would not be permitted to use genetic information under any condition and underwriting would become obsolete.

Working within the System:

- Deny health insurers the opportunity to use genetic test results, or knowledge that a person has had a genetic test, to deny insurance to healthy people.⁵
- Deny health insurers access to genetic test results or information without the consent of the person being tested even if the insurer is paying for the test.⁵

Health Insurance vs. Life Insurance:

- Clear distinction between economic and ethical considerations of health insurance and life insurance.
- Life insurance policy is “a commercial transaction in which the insurer agrees to pay a death benefit in exchange for a premium proportional to the mortality risk assumed by the insurer.”⁷

Justifications:

- As long as life insurance is an individual choice, it is only fair that insurance companies be allowed to use risk assessment in underwriting.⁷
- To be economically viable, a private insurance system must be able to identify the risks it is asked to insure, classify them into groups, and issue premiums that reflect the level of risk.⁸
- Since people will use genetic information to guide their insurance purchases, life insurance companies should have access to the same information.⁸

Faulty Reasoning by Opponents:⁸

- The argument that one's genetic profile is not one's "fault" and thus should not be used against him is not justified because life insurers are only concerned with relative mortality risk.
- Use of cardiovascular factors to estimate the chance of premature heart disease.
- Suggests that "applicants with all other disorders [are] responsible for their illnesses."

Concluding Thoughts:

- In the absence of universal health care, protective measures should be established to prevent genetic discrimination by health insurers.
- Life insurance, a privilege and not a universal right, should not be subject to the same legislation.

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