

PUBLIC OPINIONS AND CONCERNS OF GENETICS ISSUES

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Genetic Discrimination Scenario (provided for group discussion)

Genetic Screening for Alzheimer Disease

Scenario: Tom is 52 years old and his 80-year old mother recently passed away from complications related to Alzheimer disease. He's heard that there is genetic research being done on Alzheimer disease and he's interested in learning more about what testing is available. Tom is especially anxious because he feels that his older sister may be exhibiting signs of memory loss. She's 60 years old.

Tom visited a genetic counselor and was informed that a genetic test could determine whether he had a variation in a gene that would contribute to a higher risk of Alzheimer disease, with possibly an earlier onset, and increased risk for cardiovascular problems. The genetic counselor also stated that the results of this genetic test are not conclusive. If he tested positive he would not necessarily get Alzheimer disease, he'd simply know that he has a moderately greater risk for developing the disease than the general public. Likewise, if he tested negative, he could still develop Alzheimer disease later in life—a negative test would not decrease his risk to develop Alzheimer disease below the risk of the general public.

In addition, the genetic counselor suggested to him, if he didn't already have, or felt like he would ever want, life or long-term disability insurance, he should consider purchasing them prior to testing. She explained that people are protected from discrimination for purchasing health insurance by Federal and State laws, but there are no such protections for life or long-term disability insurance. She reassured Tom that there's no evidence that insurers would discriminate based on his history or possible test results but she felt compelled to raise the issue.

Tom, sensing the counselor's unease about possible discrimination asked if he should have other concerns or take further precautions? The counselor explained that some people worry about having their genetic family history or genetic test results used against them in employment situations too. Maybe not getting a job or not getting promoted because of their health history. However, the Americans with Disabilities Act (ADA) prohibits employers from discriminating against persons with disabilities in hiring practices. It's not clear how the ADA might protect an individual who has had genetic testing and who does not currently show signs or symptoms of illness—in other words doesn't currently have a disability. She again reminded Tom that there is very little evidence that people with known genetic illness or disease genes in their families are actually discriminated against. She just wanted to be sure he had thought about the issues before he underwent testing.

Background Information on Genetic Discrimination

Genetic Discrimination: Different treatment of individuals based on genetic information (e.g., genetic test results or a family history of genetic illness) prior to the onset of illness. This does not include discrimination against individuals who are currently affected by a disorder.

Privacy: An individual's right to have information remain secret (e.g., a patient has a right to keep personal health information from being disclosed to others or made public).

Confidentiality: An organization or profession's responsibility to protect private information, (e.g., a physician has a responsibility to keep a patient's personal health information secret).

Goal of Practicum Project:

- Assist the Washington State Department of Health in planning and carrying out public forums in which Washington residents can discuss issues and concerns related to genetics.
- Create background materials and discussion guides for the forums centering on genetic discrimination.
- Transcribe notes and write articles reporting on the general opinions from two forums.



Locations of Forums

What Protections Against Genetic Discrimination Currently Exist?

Insurance Discrimination

- Federal law: The Health Information Portability and Accountability Act (HIPAA) states that genetic information cannot be considered a pre-existing condition unless it related to a disease that has already been diagnosed. Therefore, patients who are covered by group health insurance plans cannot be excluded from group coverage based on genetic test results, and current subscribers cannot be refused coverage for a particular condition based on genetic test results.
- Currently, there are no federal laws that specifically address the issue of genetic discrimination in obtaining, or keeping, life or disability insurance.
- Washington State law: Health carriers may not reject health plan applicants and may not limit or exclude plan coverage for any reason associated with health risk or perceived health risk. However, coverage can be limited for several months for a condition that has already been diagnosed. Genetic information alone cannot be treated as a health condition.
- There are no state laws that address the issue of genetic discrimination in life or disability insurance. However, there is a state regulation that prohibits cancellation of a policy because of health conditions that emerge after issuance.

Discrimination in Employment Practices (i.e. hiring and promoting)

- Federal legislation: The Americans with Disabilities Act (ADA) prohibits employers from discriminating against individuals who have disabilities. It is unclear whether ADA relates to genetic discrimination in employment and until a legal case is filed, people may interpret this law differently. The ADA does not necessarily protect individuals from having to disclose genetic status to an employer.
- State Legislation: Washington State Law Against Discrimination addresses issues related to discrimination for many issues including housing and employment. Whether or not someone would be protected under this law would depend on their status in a protected class (e.g., race, religion, ethnic background, etc.). If someone with a genetic risk to develop disease was perceived as, or treated as, a person with a disability then they would be protected.

Project Description

The goal of the Living Room Forums is to solicit and report opinions and knowledge of the public on issues surrounding genetics. These forums are meant to empower Washington residents to be their best own advocates in representing their interests with regards to health care and genetics. The information derived from these forums will be shared with policy makers around the nation.

Altogether, 15 forums were performed in various locations around Washington state, each hosted at the home of a volunteer host from the community and attended by the host's friends and neighbors. Topics of discussion included genetic discrimination, access to genetic services, and newborn screening. For each forum, participants were given background information, a case scenario, and then were asked questions to facilitate the dialog.

The opinions and statements of forum participants were recorded and reported in articles in local newspapers, with the hope to generate more conversation throughout the community.

Vancouver: April 30, 2003

"I'd want to take a genetic test. My obligation is to prepare my family, and with AD you get to a stage where you can't make decisions"—Human resources researcher

"If I know my family history, I can take care that way...I don't need genetic information"—Social worker

"There are some benefits to employees to letting an employer know. If you tell the employer, he has to accommodate you, legally"—human resources researcher

"On the other hand, genetic test results might cause doubt about an employee's performance evaluation. It taints you, there are so many biases out there, such as being treated differently, or not getting up the ladder"—RN

"Are laws growing with what we want to accomplish medically? We don't have the system in the US to support genetic tests"—retired nurse

Redmond: May 12, 2003

"I want to remain blissfully ignorant. It's a personal choice... If I chose to have a test, it would be me alone, it would be mine...I want my privacy, my employer has no business knowing a predisposition for things that may or may not happen. I would be treated differently, I would treat people differently, it's human nature. How private is private?"—Principal

"Of course as an employer you want to have access to all information. If you had access to that information you could establish a profile of a better workforce with fewer health problems"—Retired participant

"One of my big fears is the purpose of [genetic tests]. If it's for me and how I could live my life, then yes. But if it's to be denied employment, or insurance, or be discriminated against, then no...It's for me personally, so that maybe I can alter my lifestyle. The purpose of the testing needs to be clarified and controlled"—Principal

"In this country, as rich as we are, there's no reason why everyone shouldn't be cared for properly in the health field. It should be one of our number one priorities"—Librarian