

Confidentiality & the Risk of Genetic Discrimination

What Surgeons Need to Know



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KEYWORDS

- Genetic discrimination • Privacy • Genetic Information Nondiscrimination Act
- Health Insurance Portability and Accountability Act • Genetic testing • Legal
- Hereditary cancer

KEY POINTS

- Federal and state laws are now in place to prohibit many forms of genetic discrimination including health insurance eligibility, coverage, and rates, and employment.
- Patient health information including genetic testing and family history are protected under the Health Insurance Portability and Accountability Act and the Genetic Information Nondiscrimination Act.
- Some groups are not covered by current regulations.
- Physicians have a duty to warn patients that they and their relatives are at risk from a genetically transferable condition, but they must rely on the patient to communicate with family members.

INTRODUCTION

Fears about genetic discrimination plague patients and providers alike. These concerns can arise throughout the genetic testing process: before testing, after results are received, and when patients are deciding what type of cancer screening or risk reduction measures they should take based on their results. Some of the major concerns expressed by patients and providers around genetic discrimination include

- “Could I lose my health insurance if my genetic test comes back positive?”
- “If I have genetic testing, will my insurance premiums increase?”
- “What if my employer finds out I’m at high risk for cancer; could I be fired or demoted?”

The authors have nothing to disclose.

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Surg Oncol Clin N Am 24 (2015) 667–681

<http://dx.doi.org/10.1016/j.soc.2015.06.004>

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- “Should I recommend genetic testing for my patient if it could cause him/her problems obtaining health insurance?”

When genetic testing for hereditary cancer risk first became clinically available in the mid-1990s, comprehensive legal protections prohibiting genetic discrimination did not exist. Both patients and clinicians were wary of the potential for genetic discrimination.

The current state of affairs in the United States is quite different. Both federal and state laws are now in place to prohibit many forms of genetic discrimination. Despite this, many patients and clinicians are unaware of these protections. A 2010 study conducted by Parkman and colleagues¹ used questions added to the Behavioral Risk Factor Surveillance System (BRFSS) survey in 4 states to assess public knowledge regarding legal protections from genetic discrimination. Only 13.3% to 19.1% of respondents indicated that they were aware of laws (such as the Genetic Information Nondiscrimination Act, GINA) that “prevent genetic test results from being used to determine health insurance coverage and costs.”¹ In 2009, Laedtke and colleagues² sent surveys to 1500 members of the American Academy of Family Physicians assessing their knowledge of GINA and their concerns regarding genetic discrimination. Of the 401 physicians who responded, over half (54.5%) were not aware of GINA, and 44% were “highly concerned” about their patients’ potential risk for genetic discrimination in health insurance.²

This article reviews the current legal protections against genetic discrimination, how they can affect both patients and their families, and perspectives on how current protections will be applied to an ever-changing genetic testing landscape. It will focus on how this information can be used by surgeons to help reassure their patients regarding the protections that exist and also educate them about loopholes where safeguards are not currently in place.

CURRENT LEGAL FRAMEWORK IN THE UNITED STATES REGARDING GENETIC DISCRIMINATION AND GENETIC INFORMATION PRIVACY

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was passed in 1990.³ The primary purpose of the ADA is to prevent discrimination against individuals with disabilities in the workplace and to set enforceable standards for accessibility in public and commercial buildings, transportation, and communication services (specifically telecommunications device for the deaf/telephone relay services).^{3,4} It provides some limited protections regarding genetic discrimination with regard to hereditary cancer predispositions to individuals employed by an employer with 15 or more employees.³ Some state laws also ban employers from discriminating against individuals on the basis of disability. If an individual has a genetic disease that causes symptoms that significantly impair a person’s ability to perform one or more functions, then their disease qualifies as a disability under the ADA.^{3,5-7} This would then afford an individual protection from employment discrimination under the ADA, as long as they are able to perform the duties of their job with reasonable accommodations. Some hereditary cancer syndromes can be associated with cognitive impairment (such as *PTEN* hamartoma tumor syndrome), which may classify as a disability for some individuals.^{8,9} Others may have experienced debilitating effects following their cancer treatment that could potentially rise to the level of a disability.^{10,11} However, most individuals with hereditary predispositions to cancer do not have disease effects that rise to the level of disability.

Confidentiality and the Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act (HIPAA) was passed in 1996. The primary goal of the law is to make it easier for people to keep health insurance

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