Genetic Information and Discrimination: A Policy Analysis

Cindy Snyder, DNP, APRN, FNP-C, CBCN®

Because of the Human Genome Project, nurses increasingly must understand how genetics impact health and treatment decisions. Although the sequencing of the human genome was crucial, the next step is advancing the understanding of genomics, interpreting genetic information, and using that information to improve health care, particularly for patients with cancer. Oncology nurses are in a position to educate and provide appropriate counseling to patients unsure about genetic testing.

The first phase of the Human Genome Project was completed in 2003; as a result, nurses must have a clear understanding of the impact of genomics and genetic information on health care, particularly cancer care. Patients and their families should be provided with information about genetic cancer-risk assessment and genetic testing when appropriate (Baer, Brawarsky, Murray, & Haas, 2010; Centers for Disease Control and Prevention, 2010; Oncology Nursing Society, 2005). However, patients often avoid genetic consultations and genetic testing because of concerns about privacy and potential adverse consequences, such as discrimination by insurance companies and employers (Baer et al., 2010).

The purpose of this article is to (a) increase understanding of the Genetic Information Nondiscrimination Act (GINA) of 2008, and (b) inspire confidence in the protection of personalized health information.

Context

The 1997 film Gattaca, written and directed by Andrew Niccol, portrays a hierarchical society based on genetic discrimination. The title of the film is derived from the first letters of the four bases that make up DNA. In the film, genetic screening is used to identify those who are genetically superior or inferior (Acheson & Wiesner, 2004; Marks, 2005).

Should society support policies for testing of hereditary syndromes that can predispose a healthy person to disease? Do the potential benefits of genetic testing outweigh the potential harms? Healthcare providers often consider that balance during decision making with their patients. Assessing family history is a low-cost, low-tech method for capturing the genetic, environmental, and behavior factors that contribute to the risk for hereditary cancer syndromes (Tranin, Masny, & Jenkins, 2003). Nurses should have an understanding of how to construct and assess a family genogram. When patterns of hereditary cancer syndromes are identified such as breast cancer in women younger than age 50, or a woman with breast and ovarian cancer, a referral for genetic counseling is appropriate. The Centers for Disease Control and Prevention’s Office of Public Health Genomics provides information and resources on family history and genetic testing at www.cdc.gov/genomics.

Although patients may be hopeful that knowing their genetic information could improve their health, they may not pursue genetic testing for fear of being stigmatized. That fear may include concern “that genetic information may be used by insurers to deny, limit or cancel health insurance, and by employers to discriminate in the workplace” (National Human Genome Research Institute [NHGRI], 2010c, para. 1). As a result, many policymakers, healthcare providers, and advocacy groups have asserted that federal legislation is needed to prevent genetic discrimination (Acheson & Wiesner, 2004; Mason, Leavitt, & Chaffee, 2007; NHGRI, 2010c; Savulescu & Foddy, 2007). Claims of genetic discrimination have been documented since the 1970s, when African American communities were tested to identify individuals who carried the sickle cell trait (Mason et al., 2007). In 2000, railroad workers in the United States were subjected to mandatory secret genetic testing to identify a possible predisposition to carpal tunnel syndrome. After a railroad worker’s wife, a nurse, discovered the secret testing, the U.S. Equal Employment Opportunity Commission filed suit under the Americans With Disabilities Act (ADA). The suit resulted in the railroad discontinuing the testing and providing a settlement to the workers (Erwin, 2009). In another case, an employee whose parent developed Huntington disease decided to undergo genetic testing, given her 50% chance of inheriting the gene mutation. As a
consequence of testing positive for the mutation and sharing the information with her employer, the employee was fired from her job. For fear of losing their jobs and health insurance, her siblings declined to undergo testing, resulting in a lifetime of uncertainty of whether they inherited the genetic mutation that causes Huntington disease (NHGRI, 2010a).

One argument against the need for legislation protecting the privacy of genetic information is that little evidence exists of violations of privacy and genetic discrimination. However, any alleged instance of genetic discrimination should be investigated objectively to determine whether federal or state laws have been violated (Mason et al., 2007; NHGRI, 2010b; Secretary’s Advisory Committee on Genetics, Health, and Society, 2005).

The first U.S. federal legislation to prevent misuse of genetic information, the Health Insurance Portability and Accountability Act (HIPAA), was enacted in 1996. At that time, only about 300 genetic tests were available and most were for rare conditions. HIPAA prohibited group health insurers from using genetic information to identify preexisting conditions (in the absence of a diagnosis) and from establishing eligibility requirements based on genetic information.

Genetic tests now are available, many in primary care clinics or directly to consumers, for more than 1,500 conditions. In 2008, GINA gave Americans the strongest federal legislative protection from genetic discrimination by health insurers and employers. With the age of personalized medicine and targeted therapies, people in the United States need to understand the healthcare policies in place to protect their genetic information.

Policy Goals and Options

GINA has been described as the “first major civil rights bill of the new century” (Hudson, Holohan, & Collins, 2008, p. 2662). Title I of the act prohibits health insurance plans, whether a group, individual, or Medicare supplemental policy, from requesting or requiring that a covered member or family members undergo genetic testing. In addition, health insurers are prohibited from requesting, requiring, or purchasing genetic information for underwriting purposes. Title I also extends HIPAA privacy regulations to genetic information, prohibiting health insurers from disclosing genetic test results for underwriting purposes (Abiola, 2008; Erwin, 2009).

Health insurance plans may request that a member or beneficiary undergo genetic testing for research purposes. Under Title I, genetic testing may be requested if the following provisions are met: (a) the plan indicates that testing is voluntary and choosing not to have testing will not affect enrollment status, (b) no genetic information is used for underwriting, and (c) the health plan notifies the U.S. Secretary of Health and Human Services of the plan to conduct testing and provides a description of the activities. In addition, health plans can request minimal information when determining coverage on a claim for a procedure, such as a prophylactic surgery performed for risk reduction (Abiola, 2008; Erwin, 2009). For example, elective oophorectomy for premenopausal women with hormone receptor-positive breast cancer may require the provision of additional information, including genetic testing.

Title II of GINA identifies discrimination against an employee based on genetic information as an illegal employment procedure. Employment agencies are banned from making referral decisions based on genetic standards. In addition, employers, employment agencies, or labor organizations cannot legally classify employees by their genetic profile or purchase an employee’s genetic information (Abiola, 2008; Erwin, 2009).

GINA does grant employers access to employee genetic information under certain circumstances, including to comply with certification requirements of family and medical leave laws, to monitor biologic effects of toxic substances in the workplace, if the employer conducts DNA analysis as part of law enforcement activity, or to identify human remains. In addition, employers may retain genetic information that is provided voluntarily by the employee (Abiola, 2008; Erwin, 2009).

Table 1. Policy Analysis: Alternatives for Protecting Genetic Information

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>ADA</th>
<th>HIPAA</th>
<th>GINA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coverage</td>
<td>All U.S. citizens</td>
<td>All U.S. citizens</td>
<td>Excludes active military and veterans obtaining health care through Veterans Affairs and Indian Health Service</td>
</tr>
<tr>
<td>Employer requests</td>
<td>Prohibits discrimination on the basis of disability, but does not explicitly protect on the basis of genetic predisposition</td>
<td>Not applicable</td>
<td>Prohibits employers from requesting, requiring, or purchasing genetic information about members or their family members</td>
</tr>
<tr>
<td>Genetics in employment</td>
<td>Prohibits discrimination on the basis of disability, but does not explicitly protect on the basis of genetic predisposition</td>
<td>Not applicable</td>
<td>Prohibits employers from using genetic information in making employment decisions (e.g., hiring, firing, job assignments)</td>
</tr>
<tr>
<td>Genetic testing requirements</td>
<td>Not applicable</td>
<td>No medical privacy clause</td>
<td>Prohibits an insurer from requesting or requiring that an individual have a genetic test</td>
</tr>
<tr>
<td>Insurance</td>
<td>Not applicable</td>
<td>Not applicable</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Premium eligibility</td>
<td>Not applicable</td>
<td>Does not apply to individual plans unless covered by portability provision</td>
<td>Prohibits group and individual health insurers from using genetic information to determine eligibility of premiums</td>
</tr>
</tbody>
</table>

Note. Based on information from Abiola, 2008; Hudson et al., 2008; Mason et al., 2007; National Human Genome Research Institute, 2010b.
Evaluation of Policy Options

State laws, HIPAA, and ADA provide only partial protection of genetic information. To evaluate GINA, state laws, HIPAA, and the ADA for criteria on successfully protecting genetic information, a policy analysis is provided in Table 1. According to the analysis, GINA provides the most comprehensive protection from employer and insurer discrimination practices. However, additional regulations are needed to address life, disability, and long-term care insurance (Abiola, 2008; Erwin, 2009; Hudson et al., 2008).

Implications for Clinical Practice

Assessing familial risk for cancer, identifying genetic markers, and providing personalized care with targeted therapies are important components of modern cancer care. Nurses can assist in decisions related to practice, education, and the quality of cancer care by understanding how genetic information affects individuals, family, and society (Tranin et al., 2003). Oncology nurses play a key role by educating patients and their families about genetic testing and providing appropriate counseling, including protection of genetic information. Understanding policies such as GINA, ADA, and HIPAA can help oncology nurses provide the necessary education and reassurance to patients and their families. Additional information about GINA can be found in Steck and Eggert (2011), and additional resources on genetics and genomics can be found at www.genome.gov, http://healthypeople.gov/2020, and www.ncbi.nlm.nih.gov/sites/Genetests.

Author Contact: Cindy Snyder, DNP, APRN, FNP-C, CBCN®, can be reached at csnyder@gwinnetmedicalcenter.org, with copy to editor at CJONEditor@ons.org.

References