

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

Cindy Snyder, DNP, APRN, FNP-C, CBCN®, is the manager of oncology services and a certified breast cancer care nurse at Gwinnett Medical Center in Lawrenceville, GA. The author takes full responsibility for the content of the article. The author did not receive honoraria for this work. No financial relationships relevant to the content of this article have been disclosed by the author or editorial staff.

Digital Object Identifier: 10.1188/11.CJON.330-332