

Oncology nurses are advocates for the ethical and legal use of patients' genetic information. However, this information may be used to discriminate against individuals when they share it while participating in workplace wellness programs. Amendments to federal genetic discrimination laws may lead employees to being financially penalized for nondisclosure of their genetic information. This article stresses the importance of nurses being aware of these laws and pushing for policy revision to protect sensitive genetic information.

AT A GLANCE

- Oncology nurses, along with their patients and families, need to be informed about the provisions and limitations of federal genetic discrimination laws.
- Oncology nurses must educate patients about how participation in their employers' workplace wellness programs gives employers and third parties access to their genetic information.
- Healthcare providers, particularly oncology nurses, should push for policy changes related to federal genetic discrimination laws (e.g., programs should be required to report their effectiveness to federal regulators, genetic information should be disclosed only to healthcare providers).

KEYWORDS

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Workplace Wellness Programs

Educating patients and families about discrimination via disclosure of genetic information

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Oncology nurses routinely take family medical histories and follow clinical guidelines that may include recommendations that their patients undergo genetic testing for risk assessment, diagnosis, treatment, and management of malignancy. However, this genetic information (i.e., family medical history that includes the patient's spouse and children and the patient's genetic testing results) may inadvertently be disclosed to the patient's employers and insurance companies, leading to potential discrimination (National Human Genome Research Institute [NHGRI], 2015; Sarata, 2015). Oncology nurses are charged with safeguarding their patients' genetic information, as is reflected in the Oncology Nursing Society's ([ONS's], 2016) position statement on the subject, which states that oncology nurses "advocate for the ethical and legal use of genetic and genomic information" (p. 1). In addition, oncology nurses need to be aware that their patients' genetic information, as well as their own, may be used for discriminatory purposes when they elect to participate in workplace wellness programs. The purpose of this article is to describe voluntary workplace wellness programs and how the genetic information of patients with cancer and their spouses, along with the genetic information of nurses, may be used within these programs to potentially discriminate against them.

Wellness Programs

The establishment of voluntary wellness programs, which are also known as employer-sponsored, employee, or workplace wellness programs, was recommended in the Patient Protection and Affordable Care Act of 2010 (PPACA), with provisions implemented in January 2014. Employers, particularly large employers with more than 200 employees, were encouraged to establish wellness programs to promote their employees' health and prevent disease, with the ultimate goal of motivating employees to adopt healthier lifestyles (Roberts, 2017; Rosenbaum, 2011). After an employee voluntarily enrolls in a wellness program, he or she completes health risk assessment questionnaires and undergoes biometric screening (e.g., weight, blood pressure, cholesterol levels) (Roberts, 2017). The PPACA outlines recommendations to establish two types of voluntary wellness programs: participation-based and health-contingent wellness programs. Neither type of program is required to be evidence-based, and both are unregulated—organizations do not have to report the efficacy of their wellness programs (i.e., improvement in participants' health) to any federal regulator (Hudson & Pollitz, 2017).

Participation-based wellness programs must be offered to all employees. Incentives for employee participation in this type of program may include free or reduced gym memberships, free diagnostic testing, and/or tobacco cessation