Issues Related to the Use of Genetic Material and Information

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Purpose/Objectives: To review issues regarding the use of genetic materials and information.

Data Sources: Professional literature, regional and federal legislation.

Data Synthesis: An analysis is provided of the relationship among advances in genetic technology, use of genetic material and information, and the development of laws that protect the interests of donors, researchers, and insurers. Rapid technological achievements have generated complex questions that are difficult to answer. The Human Genome Project began and the scientific discoveries were put to use before adequate professional and public debate on the ethical, legal, social, and clinical issues. The term "proper use" of genetic material and information is not defined consistently. An incomplete patchwork of protective state and federal legislation exists.

Conclusions: Many complicated issues surround the use and potential misuse of genetic material and information. Rapidly advancing technology in genetics makes it difficult for regulations that protect individuals and families to keep pace.

Implications for Nursing Practice: Oncology nurses need to recognize their role as change agents, understand genetic technology, and advocate for patients by participating in the debate on the proper use and prevention of misuse of genetic material and information.

Key Points . . .

- ➤ Scientific advances in the area of genetic diagnosis and research have resulted in numerous ethical and legal dilemmas.
- ➤ Scientific discovery outpaces the ability of policy- and lawmakers to keep current.
- ➤ Healthcare professionals must be aware of and understand the ethical implications of genetic testing and the disposition of the results of such testing.
- ➤ Issues involving ownership of genetic material and results of testing, the uses to which the material and information can be put, and the availability of this material for scientific study must be determined in a way that benefits society and the individual.

The rapid expansion of opportunities for genetic predisposition testing has generated complex questions about the nature of appropriate relationships among providers, researchers, patients, and insurers. Soon after the National Institutes of Health (NIH) and the United States Department of Energy (DOE) conceived the Human Genome Project in the mid-1980s (Kevles, 1992; Organization for Economic Cooperation and Development, 1995), those involved identified the potential for discrimination based on knowledge of genetic predisposition to cancer or other diseases. Advances in gene technology have generated a flurry of debate about the proper and improper use of genetic material (e.g., DNA samples, cell lines, tissues samples) and information (e.g., test results, family pedigrees).

The discussion has intensified as genetic testing has become commercially available and offered by primary practitioners. A need exists for ongoing consideration of the evolving issues and comprehensive federal and matching state legislation that defines the proper use of and prevents the misuse of genetic material and information. Cancer is used as the prototypic genetic disease for examination of these issues.

Genetic Predisposition to Cancer

More than one million people are diagnosed with cancer each year in the United States (American Cancer Society, 2000). Genetic alterations predispose individuals to the development of cancer, and 50,000–100,000 new cases of cancer each year in the United States can be traced to inherited susceptibility (Offit, 1998).

Inherited susceptibility is capable of conferring a high lifetime risk of cancer development. Every organ system may develop malignancies that are attributable to genetic alterations, and more than 30 hereditary cancer syndromes exist. The most common hereditary neoplasms are breast, ovarian, prostate, skin, and colon cancers. Many of the chromosomal loci for these cancers have been identified. For example, hereditary breast and ovarian cancers are associated with mutations to the BRCA 1

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