

Practice Considerations in Providing Cancer Risk Assessment and Genetic Testing in Women's Health

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ABSTRACT

Providers of women's health services are often confronted with questions about cancer genetic testing. The provision of these services is complex. The process begins with accurate risk assessment and identification of individuals who might benefit from genetic testing services. There are practice, administrative, legal, and ethical considerations that should be considered when developing policies for the referral of at-risk individuals or before deciding to provide genetic services.

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The increased availability of cancer genetic predisposition testing has created many challenges and practice considerations for providers of primary care and women's health services. Genetic tests are now routinely available and ordered to determine risk for developing and appropriate management of hereditary breast and ovarian cancer (HBOC), hereditary nonpolyposis colorectal cancer, familial adenomatous polyposis, hereditary melanoma, and pancreatic cancer, and many other hereditary cancer syndromes. Women often ask about and request that providers order these commercially available and sometimes commercially advertised genetic tests. The increased availability of cancer genetic predisposition testing has moved genetic testing away from credentialed genetics professionals to primary care and women's health nurse practitioners (WHNP). Although it might appear to be more efficient to order the test for the woman, there are a number of limitations and possible safety and legal risks with this approach; consideration of referral to a credentialed genetics professional might be more appropriate.

Credentialed Genetics Professionals

There are different types of credentialed genetics professionals. Some genetics professionals subspecialize in a specific area such as preconception, pediatric, or cancer; others provide a broader range of services. This often depends on the practice setting.

Geneticists are physicians with board certification in genetics from the American Board of Medical Genetics. They complete a fellowship in genetics and pass a board examination. An active list of board-certified geneticists that is searchable by name and/or location is available from the American Board of Medical Genetics.

Licensed genetics counselors are health care professionals with specialized graduate degrees in the areas of medical genetics and counseling. Currently there are more than 30 accredited programs in genetic counseling in the United States. The American Board of Genetic Counseling certifies genetic counselors. The National Society of Genetic Counselors maintains an active website

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in which health care professionals and the public can identify credentialed genetics professionals by zip code.

Credentialed genetic nurses have specialized education and training in genetics and are credentialed by the Genetic Nursing Certification Commission (GNCC) after evaluation of a portfolio. Nurses who are prepared with a master's in nursing who complete specialized education and training may qualify for the advanced practice nurse in genetics credential (APNG) following submission of an acceptable portfolio. To obtain this credential an advance practice nurse (APN) must submit (a) proof of at least 300 hours of genetic practicum experiences as a clinical genetic nurse with greater than 50% genetic practice component, (b) documentation of a log of 50 cases demonstrating provision of genetic nursing care within 5 years of the application, (c) four written case studies reflecting International Society of Nurses in Genetics (ISONG) Standards of Clinical Genetics Nursing Practice (International Society of Nurses in Genetics and American Nurses Association, 2006), (d) graduation from an accredited graduate program in nursing, and (e) 50 hours of genetic content in the past 5 years through academic courses or continuing education. The APNG credential also requires evidence of patient and family teaching in the clinical setting as well as evidence of education of nurses and other professionals, and consumers in the community setting. The credentialing committee also considers published abstracts, abbreviated reports, a listing of publications, and related materials in determining if the candidate is eligible for the credential. All of these materials are submitted in a portfolio that is evaluated and the credential is awarded to those who demonstrate genetic competence (Monsen, 2005)

Standards for Providing Genetic Services

A genome is the sum total of all an individual organism's genes. Genomic studies include endeavors to determine the entire DNA sequence of organisms and their function. Genetics deals with the molecular structure and function of an individual gene. Genetics is the study of the transmission of single genes within families and the analysis of more complex types of inheritance.

The development of genomic competencies and the integration of these competencies into academic programs is the first critical step toward en-

surging health care providers have the necessary knowledge and skills to provide genomic health care in the clinical setting. These competencies apply to all nurses and WHNPs should be aware of these competencies and consider how they will implement them into their practice.

A vital first step in assuring genetic competency has been initiated by National Coalition for Health Professional Education in Genetics (NCHPEG), a coalition of organizations established in 1996 of interdisciplinary worldwide leaders from more than 50 diverse health professional organizations, consumer and volunteer groups, government agencies, private industry, managed care organizations, and genetics professional societies. In 2001 they issued the *Core Competencies in Genetics Essential for all Health-Care Professionals*, which were revised in 2007 (Jenkins et al., 2001; National Coalition for Health Professional Education in Genetics, 2007).

The International Society of Nurses in Genetics with the American Nurses Association published *Genetics/Genomics Nursing: Scope and Standards of Practice* in 2007 (International Society of Nurses in Genetics, 2007). This publication discusses certification of nurses in genetics, provides definitions of genomic and genetic nursing care, defines levels of practice, and details regarding standards of practice for basic genomic care, and advance practice roles.

In the United States, the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition* define the minimum genetic and genomic competencies for all nurses in the United States (Jenkins, 2009). First published in 2006, these widely accepted competencies have been endorsed by more than 50 different nursing organizations and have prompted recent efforts to increase genomics in undergraduate nursing programs.

In 2012, *the Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees* were published (Greco, 2012). These competencies focus on the following areas: (a) risk assessment and interpretation; (b) genetic education, counseling, testing, and disclosing results; (c) interpretation of genetic testing results; (d) clinical management; (e) ethical, legal, and social implications (ELSI); (f) professional roles; (f) leadership roles; and (h) research utilization. Nurses have a professional responsibility to be familiar with these guidelines. They are all free and readily accessible

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