International Society of Nurses in Genetics

Access to Genomic Healthcare: The Role of the Nurse

(Approved: September 9, 2003, Revised: April 15, 2010)

Background

Since the completion of the Human Genome Research Project in 2003 the pace has accelerated in the clinical application of genetics to healthcare science. These applications (genomic health services) transform the way patients, healthcare providers, and healthcare insurers define health and well being. With a new paradigm for health and well being comes a new conceptualization of healthcare services that include consideration for the impact of genetics and genomics on etiology, predisposition for disease, incidence, treatment and treatment outcomes. As a result of technological advances, healthcare needs, and a growing interest among the public there is an increasing number of people considering genomic healthcare

A broad definition of genomic healthcare proposed by Guttmacher and Collins (1) includes the study of the functions and interactions of all the genes in the human genome, including their interactions with environmental factors. At present, there are three essential elements of genomic healthcare: infrastructure necessary to provide genomic healthcare, knowledge required by healthcare providers and consumers to appropriately offer or act on genomic information, and equitable allocation of genomic services within healthcare systems. (2) There is, however, a considerable lag in the time it takes to transfer knowledge from the bench to the bedside. The delay is sometimes justified by the newness of the science and intention of health professionals to utilize reliable and validated findings. However, the delay is also caused by the slow and inconsistent dissemination of findings to health professions and thus to consumers.

In 1988, The Institute of Medicine (3) identified three core functions of public health. They are: (a) the assessment of health and health behaviors; (b) the development of policies to inform, educate, and empower consumers; and c) the assurance of appropriate integration of genomics into healthcare services and strategies for genomic public health. Nurses have a role in all three. (4)) With appropriate planning, funding and allocation of resources, barriers to equitable access to genomic healthcare services can be overcome. (5) Facilitators to realization include: legal protection from discrimination and access to health care regardless of socioeconomic status geographic location, ethno-cultural beliefs, or genetic literacy (4).

Nurses in all practice settings address patients' genomic healthcare concerns. This requires knowledge of genetic evaluation, research and treatment development and participation at in policy and program development. Nurses share with other healthcare professionals the responsibility to ensure equal access to genetic and genomic information, and genomic healthcare services.

The Codes of Ethics for Nurses developed by the International Council of Nurses (6) and the American Nurses Association (7) state that nurses have a shared responsibility with other health professionals and society to ensure initiation and promotion of community, national, and international efforts to meet the health and social needs of the public. This includes the right to seek and receive genomic healthcare that is nondiscriminatory, confidential, private, and that ensures the opportunity for nondirective informed decision-making. As providers in all practice settings, nurses must advocate for and fulfill a central role in the assessment, policy development and assurance of universal access to genomic healthcare by all populations regardless of genetic literacy (6), socioeconomic or ethno-cultural background. Nursing competency standards exist across countries and nursing specialty organizations. These provide an additional layer of expectations for bringing nursing competency to considerations of population access to genomic healthcare and research. (8)

The International Society of Nurses in Genetics, Inc. (ISONG) recognizes the application of genetics to nursing practice (9). The standards of nursing practice focus on assuring competent nursing care to all individuals, families or communities with, or at risk for, a genetic disorder or disease. The genetics clinical nurse fulfills this responsibility by the identification of genetic risk factors, nursing interventions, information, services, referrals or promotion of health behaviors to enhance the health and well being of the individual or family seeking care. The advanced practice genetic nurse further fulfills this responsibility through the provision of genetic counseling and case management for those with, or at risk for, a disease. The nurse scientist brings genetic competency to developing and implementing research aims, methods and findings with consideration of equitable access of vulnerable and historically marginalized populations and ethical, legal and social implications of genomic healthcare research.

To fulfill the right of the public to access genomic healthcare services and research without fear of discrimination, the basic and advanced practice genetic nurse's responsibility extends to the development of partnerships with other stakeholders such as patients, healthcare providers, insurers, and governments officials.

To ensure equitable access to genomic health care, these partnerships should:

- Ensure the right of all seeking care opportunities to participate in the process of informed decision-making (10).
- Mandate the management of genetic information in order to adhere to and fulfill the principles of confidentiality and privacy (11).

- Ensure the protection of vulnerable and historically marginalized populations in order to promote and safeguard their participation in healthcare (11).
- Eliminate discriminatory insurance practices based on the outcome of genetic testing and/or evaluation of one's genetic history.
- Identify and adopt diagnosis and reimbursements applicable for genetic tests, genetic education, genetic counseling and management of genetic conditions.
- Promote the timely validation and approval of new genetic tests to ensure reimbursement for expenses incurred while providing services.
- Create opportunities whereby nurses from diverse backgrounds will receive genetic education to enhance culturally appropriate genetic health services.
- Develop evidence-based systems of health care that offer equitable genetic/genomic services to all populations.

It is the position of ISONG that nursing will promote equitable access to genomic healthcare through the following:

- Recognize and acknowledge the role of genomics as an integral component in the promotion of the public's health and well being.
- Advocate and promote the right of the individual to seek genomic healthcare services.
- Evaluate and support legislation that provides protection from health insurance and employment discrimination at the state and federal levels.
- Identify and seek solutions to the elimination of barriers to accessing genomic healthcare.
- Advocate equal access to genomic healthcare and services development.
- Implement continuing higher education programs in genetics for nurses to improve and maintain their genetic and genomic science knowledge base.
- Establish and evaluate practice settings for provision of genetic counseling, genetic education, or other genomic healthcare services to meet the needs of the patient population.
- Integrate into clinical practice genetic and genomic research findings that promote the equitable health care offered to all individuals and families.
- Participate in strategic planning that creates partnerships for the delivery of genomic healthcare within and between the public and private sectors.
- Conduct or participate in research studies that attempt to describe and explain the interactions of genetic susceptibility and environmental factors.
- Educate the public about genomic healthcare and genomic healthcare services using school-based and community-based educational programs.

References

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