A Genetic Services Practice Model: Advanced Practice Nurse and Genetic Counselor Team

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Genomics or the interaction of one's genes and the environment is changing our concept of health and disease, available therapies, use of genetic testing, and related societal ramifications. As genomics integrates into all aspects of health care, the demand will increase for meaningful interpretation and application of the new genetic information. To meet this demand, new service delivery models must be considered. Nurse practitioners and genetic counselors are midlevel providers that can, together, provide clinical evaluation, case management, follow-up, and the genetic counseling aspects of a comprehensive medical genetics consultation. Midlevel providers working with a medical geneticist can expand access to this level of expertise, thereby reaching more patients and consumers. This nurse practitioner–genetic counselor practice model is described in the context of a rural setting.

Keywords: Genetic counselor; Genetic nurse; Genetic outreach clinic; Rural health care; Access to care; Practice model

Genomics or the interaction between one's genes and the environment is changing our concept of health and disease. It is also impacting the developmental and availabilities of new therapies, expanding genetic testing while at the same time increasing ethical, legal, and social implications of these genetic tools.[1,2] Researchers, clinicians, educators, patients, and ethicists strive to unlock the genome's secrets, anticipate the impact, and prepare for the incorporation of genomics into all facets of health care. The relatively small genetics workforce (eg, medical geneticists, genetic counselors, and genetic nurses) prompts real concern about appropriate integration of genomics information into patient care. This concern has promoted educational interventions and innovative practice models.[1-5]

This article describes a practice model that involves a genetic counselor and a nurse practitioner partnering to care for a rural population of patients with known or suspected genetic conditions. This model as developed by the genetic counselor and nurse practitioner collaboration is, to our knowledge, novel in its approach.

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Background

Recent advances in DNA technology are rapidly transforming our ability to understand the molecular and biochemical underpinnings of disease processes. Collectively, the Human Genome Project, the International HapMap project, and the Cancer Genome Atlas Pilot Project[2] are expected to speed the transition of knowledge and technology from "bench to bedside" and provide practitioners with rapidly expanding information in the areas of genomics and proteomics. These projects aim to map our human genes, polymorphisms indicative of increased risk for disease, and genes contributing to cancer, respectively. This is undeniably a new paradigm for understanding health and disease processes.

Since the 1990's, genetics and bioethics professionals have worked diligently to educate primary care professionals, public health officials, organizations (such as the health insurance industry), lawmakers, and the public about the advantages as well as risks in the appropriate use of genetic information. Much of this work culminated in the development by the National Coalition of Health Professional Education in Genetics of genetics competencies for nurses, public health officials, and other health care providers.[3,4,6]

The public is currently being challenged to gain competency in their own families' health history and to present that information to their health care providers,[4] who are not yet ready to interpret or store this information. In addition, the

technology of tandem mass spectrometry (ms/ms) is pushing the detection of disorders in the newborn period beyond the existing genetics workforce capacity to educate families and treat affected infants. Thus, both an understanding at the molecular level and the ability to make that information meaningful for the individual and family is requisite to achieve the promises of this knowledge and resulting technological advances. Without specifically trained professionals, individuals and families are left to gather information, educate themselves, and make decisions regarding medical interventions that may be difficult even for medical professionals. Thus, the public must be able to access these appropriately trained health professionals.

Three national inventories of the genetics workforce were conducted by Cooksey, et al.[7-9] Their studies of medical geneticists, genetic counselors, and genetic nurses found that expansion of genomics knowledge and its clinical application is beyond the current genetics workforce capacity. In 2003, there were approximately 1500 boarded, active medical geneticists in the United States.[7] The National Society of Genetic Counselors 2006 annual report indicates 1912 full members of National Society of Genetic Counselors.[10] The International Society of Nurses in Genetics reports 290 full members residing in the United States in July 2007.[11] This translates into approximately 1 provider per 1.2 million persons living in the United States. Furthermore, few physicians are entering clinical genetics residencies,[12] which could further hamper access to these specialists.

One potential solution to this shortage is to use genetic counselors and genetic nurses more effectively. Genetic counselors are master's educated health professionals trained specifically to provide information about the inheritance and natural history of genetic conditions, interpret and explain the significance of genetic screening and testing results, analyze family history, and provide supportive counseling and resources to those affected by hereditary conditions. Genetic counseling graduate programs provide an educational background in basic science, psychosocial counseling, and research with significant experience in supervised clinical settings. Graduates achieving certification must pass 2 board examinations: 1 in core knowledge of medical genetics and 1 in the genetic counseling subspecialty. Advanced practice nurses are similarly educated.

Education and training for certification and licensure as an Advance Practice Nurse (APN) begins with a bachelor degree in nursing and state licensure as a registered nurse (RN). The RN is eligible to apply to an accredited university, college, or school of nursing. Acceptance into a 2-year specialty program requires 42 graduate semester hours including 700 clinical hours. Upon completion of coursework, the graduate is awarded a Masters of Science in Nursing and titled with a specialty of study, such as a Family Nurse Practitioner. Other possible specialties include Pediatric, Adult, Women's Health, Geriatric, Acute Care, or Psychiatric and Mental Health Nurse Practitioner. Each specialty completes a written examination and, upon passing, earns national board certification within the selected specialty.

Through International Society of Nurses in Genetics[13] the APN can receive specialty credentialing as an APN in Genetics (APNG). An APNG provides similar services as genetic counselors: construct a family health history, assess and analyze hereditary and nonhereditary disease risk factors, provide genetic information and psychosocial support to individuals and families, facilitate genetic testing, and interpret genetic testing and laboratory results. However, most nurses working in genetics do not have the APNG designation.[14] Rather, most are RNs who have learned genetics on the job or work in a specific area of genetics such as prenatal, cancer, or metabolic genetics.

Thus far, we have established the impact of genomics in medicine, the shortage of medical geneticists to meet the needs of all those affected, and the need for primary care provider education in genetics. The genetics program described in this article was based in a rural region of southern Missouri. Integrating genomics into medical practice in rural regions highlights many of the challenges in rural health care delivery. According to the National Rural Health Association, obstacles faced by health care providers and patients in rural areas are vastly different from those in urban areas. For rural Americans, health care disparities not only include socioeconomic factors, cultural differences, and educational shortcomings but also lack of recognition by legislators and the personal isolation that can accompany living in remote areas. All these factors impede rural Americans' access to health care.[15]

Program Design

Southern Missouri Regional Genetics Service

The Southern Missouri Regional Genetics Service was established in 1995 as a satellite office of the University of Missouri (Columbia) Department of Child Health, Division of Medical Genetics. The purposes of this regional program were to (1) coordinate clinical genetics evaluation and counseling services, (2) provide professional and lay education, and (3) identify gaps in services for patient and families with genetic conditions. Before establishing this regional program, the University of Missouri held 3 outreach clinics in the region and then added an additional outreach clinic at the satellite office.

The satellite office was located in the center of a 42-county region in rural southern Missouri. The 7 counties surrounding the office constituted a “hole” in referral patterns within that region and were the counties most distant from outreach clinics. The satellite office was located 3–6 hours from Missouri's 4 tertiary medical centers with medical genetics programs.

Initial funding for this program was provided by the Missouri Department of Health. Four years later, the Genetic Services Branch of the Health Resources and Services Administration awarded the University of Missouri a 3-year grant (1 H46 MC 00161) to improve the accessibility, acceptability, and availability of genetic services in rural southern Missouri. The ultimate goal was to develop a new practice model for the delivery of genetic services in rural regions and investigate the role of a genetics program serving as a medical home for children with genetic disorders. One assumption of this program was that a genetic counselor and an advanced practice