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Establishing the Essential Nursing Competencies for Genetics and Genomics

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Abstract

Purpose: To describe the development and process of consensus used to establish essential genetic and genomic nursing competencies relevant to the entire nursing profession in the United States (US) regardless of academic preparation, role, practice setting, or clinical specialty.

Organizing Construct: Rogers' diffusion of innovation theory applied to the adoption of genetics and genomics as the central science for health care.

Methods: Multiphased national nursing initiative to develop, refine, and establish with consensus essential competencies in genetics and genomics for all nurses.

Findings: Genetics and genomics have emerged as the central science for health care in the 21st century, transforming recommendations for nursing education, practice, regulation and quality control.

Conclusion: The Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics indicate the minimal criteria for competency in genetics and genomics for the entire nursing profession in the US.

Keywords

competencies; genetics; genomics; nursing education

The elucidation of the genetic and genomic basis of health and illness has been the catalyst for unprecedented progress in scientific and clinical research in the past decade (Collins, Green, Guttmacher, Guyer, 2003; International Human Genome Sequencing Consortium, 2004). Collins noted that the human genome can be a book with many uses. "It's a history book: a narrative of the journey of our species through time. It's a shop manual, with an incredibly detailed blueprint for building every human cell. And it's a transformative book of medicine, with insights that will give healthcare providers immense new powers to treat, prevent, and cure disease" (Collins, 2006, p.1).

Remarkably this scientific progress is not limited to understanding a single condition or conditions, but has led to expanded care options across the entire spectrum of healthcare. Most health conditions have been identified as having a genetic or genomic component that is influenced by environmental, lifestyle, and other factors (Guttmacher & Collins, 2003). When synthesizing the emerging evidence, genetics and genomics redefines traditional health and illness approaches, and genomics has become the central science for all health professionals in the 21st century. The purpose of this paper is to describe the first step to address the challenge of preparing the nursing workforce for this 21st century care model integrating genetics and genomics by identifying essential nursing competencies relevant to the entire nursing profession in the US, regardless of academic preparation, role, practice setting, or clinical specialty.

Background

Since the 1980s, a few nurses have had the vision to appreciate the implications of genetics and genomics for future health care and nursing practice and have called for integration of genetics into nursing curricula, National Council Licensure Examinations, continuing education, and certification (Anderson, 1996). In 2000 an expert panel, convened by the Health Resources and Services Administration (HRSA) emphasized the importance of integrating genetics content into nursing curricula to provide an adequately educated nursing workforce now and for the future (Health Resources and Services Administration, 2000). However, the evidence shows that despite recommendations and initiatives worldwide to educate nurses, the progress of nursing competency in genetics and genomics remains limited (Edwards, Maradiegue, Seibert, Macri, & Sitzler, 2006; Hetteberg, 1999; Prows, Glass, Nicol, Skirton, & Williams, 2005). Several years since that recommendation, genetic and genomic content is still inconsistently incorporated into entry-level nursing programs, NCLEX, and certification examinations.

In a follow-up survey on the amount of genetic and genomic content in the curricula of basic nursing academic programs, no increase in genetic and genomic content was found when compared to a similar survey conducted in 1996 (Hetteberg, Prows, Deets, Monsen, & Kenner, 1999). As of fall 2005, only 30% of academic nursing programs contained a curriculum thread in genetics and genomics (Edwards et al., 2006; Maradiegue, Seibert, Macri, & Sitzler, 2005; Prows, Calzone, & Jenkins, 2006). Not surprisingly, a recent survey of advanced practice nurses showed that the majority reported they had minimal training and knowledge in genetics (Maradiegue et al., 2005), and other evidence has indicated that some nurses have limited appreciation of the relevance of these discoveries to their practice (Pfeil & Luo, 2005). Thus, the nursing profession is not fully competent in the genetics and genomics of health care despite existing resources, established competencies in genetics and genomics for all health professionals, and published model curricula (Prows et al., 2005).

Many factors contribute to this limited progress. The relevance of genetics and genomics to nursing practice is not fully appreciated and many nurses still consider it a subspecialty that is not relevant to the entire profession. Existing lists of competencies were long and not realistically achievable, given packed curricula and busy professionals with limited time and resources for continuing education. Insufficient numbers of faculty are prepared to teach

this content. Accrediting bodies do not consider genetics and genomics in their evaluations. And state boards of nursing do not require competency in genetics and genomics as part of licensure or relicensure (Burke, 2006; Prows et al., 2005). Overcoming these barriers represents an extraordinary challenge given the size and broad disparity of the nursing workforce and requires initiatives aimed at expanding existing initiatives and a centralized, coordinated, evidence-based approach.

The framework from the literature on diffusion of innovation indicates that disseminating, implementing, and sustaining new innovations depends largely on sufficient knowledge of the innovation to progress through the phases of adoption (Rogers, 1962, 1971, 1983, 1995, 2003). Within this context, the rate of progress for incorporating genetic and genomic advances throughout the continuum of health care pertains not only to technologic advances, which have progressed at an exponential rate, but also to healthcare providers' expertise in genetics and genomics to translate these findings into practice. Progress is especially complicated in nursing considering that the average age of registered nurses in the US has increased substantially. RNs younger than 40 have decreased from 52.9% in 1980 to 31.7% in 2000 to 26.6% in 2004 (U.S. Department of Health and Human Services, 2005). This shift is relevant in that older nurses are less likely to have had any genetic and genomic content in educational programs (Scanlon & Fibison, 1995). Yet this group is faced with the greatest implications of genetic and genomic advances.

With 2.9 million practicing nursing in the US, educating nurses in a new science is a daunting prospect. Yet efforts to train the nursing workforce in the United Kingdom (UK), where the average age of nurses is 42, have yielded some success (Royal College of Nursing, 2005). Their strategy began with a key concept, simplicity. Using a process of consensus, they established seven measurable, simple, and achievable essential competencies applicable to the entire nursing profession in the UK (Kirk, McDonald, Anstey, & Longley, 2003). Since that time, the U.K. National Health Service established a multidisciplinary NHS National Genetics Education and Development Centre (<http://www.geneticseducation.nhs.uk>) to support genetics education initiatives, provide educational resources for educators, and serve as a centralized clearinghouse for genetic resources and materials for all disciplines, including nursing. In addition, the participants in the Centre identify gaps in educational initiatives or materials and work to develop needed and appropriate resources.

The model adopted in the UK of honing down the expected competencies to those most essential and applicable to the entire profession is a compelling approach. First, narrowing the field of expected competencies to just seven overcomes some of the barriers to incorporation into curricula as the content becomes more manageable and preparing faculty is more reasonable. Second, nursing leaders in professional organizations have realistic achievable competencies from which to plan for continuing education for practicing nurses. Although the countries' healthcare systems are different, the efforts in the UK inspired U.S. nurses and provided a model by which to begin to address the U.S. nursing workforce's needs.

Methods

In 2004, the National Human Genome Research Institute (NHGRI) and the National Cancer Institute (NCI) of the National Institutes of Health (NIH) joined together to begin planning for a broad genetic and genomic training initiative for the U.S. nursing workforce. This collaboration was based in large part on the overwhelming need for oncology nurses to become proficient in genetics and genomics, because this specialty is one in which the application of genetics and genomics into practice is already occurring. Comparable to the UK approach, an initiative was launched to define the essential genetic and genomic competencies for all registered nurses in the US, regardless of academic preparation, role, or clinical specialty.

The first step was to establish a steering committee that included nursing leaders from clinical, research, and academic settings, including other NIH institutes and U.S. DHHS agencies, as well as nursing leaders from professional nursing organizations. Table 1 shows steering committee members and their affiliation. The role of the steering committee was to determine a mechanism for establishing essential nursing genetic and genomic competencies and achieving consensus from the nursing community.

In conjunction, ongoing efforts were underway to obtain funding to support the competency development and consensus process. Funding was obtained from the NHGRI and from the Office of Rare Disease.

Competency Development

The steering committee identified, reviewed, analyzed, and compared competencies recommended in published and peer-reviewed literature (American Association of Colleges of Nursing, 1996, 1998, 2001; Centers for Disease Control and Prevention, 2001; International Society of Nurses in Genetics, 1998; Jenkins, Dimond, & Steinberg, 2001; Jenkins, Prows, Dimond, Monsen, & Williams, 2001; National Coalition for Health Professional Education in Genetics, 2000). These documents indicated competency recommendations targeted at diverse audiences including all healthcare professionals, those in specialty genetics practice, and a subset of nurses with bachelor's degrees, advanced practice nurses, and public health professionals. A writing group consisting of members of the steering committee was established to analyze and synthesize these documents to identify fundamental genetic and genomic competencies applicable for all registered nurses. A draft of the competencies was reviewed and approved with modifications by the steering committee.

For a second level of review, the draft competencies were presented to nurse representatives to the National Coalition for Health Professional Education in Genetics (NCHPEG) in January 2005. The revised draft was posted by the American Nurses Association (ANA) for public comment in 2006. This posting included announcements to ANA members, organizational affiliates, and the members of the Nursing Organization Alliance. In an extensive period for public comment, only 10 public comments were received, most indicating support for the competencies. All comments were recorded and reviewed by the

writing group, and appropriate revisions were made. A final draft of the competencies was reviewed and approved by the steering committee.

Process of Consensus

The final aspect of consensus was an in-person meeting with key stakeholders from the nursing community. Stakeholders included representatives from certifying and accrediting bodies, National Council of State Boards of Nursing, minority nursing organizations, and professional nursing organizations. All members of the Nursing Organizations Alliance were invited to send representatives. On September 21 and 22, 2005, 50 key stakeholders convened to learn more about genetics, genomics, and the implications for nursing practice, as well as to review, revise, and come to consensus on essential genetics and genomic competencies for the entire U.S. nursing workforce. By the end of the meeting unanimous consensus was achieved. Additional information about the meeting, speakers, and the initiative can be found at <http://www.nursingworld.org/ethics/genetics/>

In summary, the essential competencies (Table 2) do not represent the opinions or position of a single nursing organization or government body. Instead, the competencies were developed by an independent panel of nurse leaders from clinical, research, and academic settings. The competencies expand existing standards of nursing practice by specifying genetic and genomic knowledge and skills for all nursing education and practice.

Results

At the September 2005 meeting, discussion occurred about specific competencies based on common definitions that are foundational to nurses' understanding of the expectations in the *Essentials* document. Two key definitions are: (a) genetics: study of individual genes and their effects on relatively rare single gene disorders (Guttmacher & Collins, 2002); and (b) genomics: study of all the genes in the human genome together, including their interactions with each other, the environment, and other psychosocial and cultural factors (Guttmacher & Collins, 2002). These two definitions remain a work in progress because the new knowledge produced by genome research will create an ongoing need to assess and revise understanding of the influence of genetic and genomic factors for health outcomes. For the purpose of the *Essentials* document, both genetic and genomic information are used as the context for defining required competencies. Additionally, the following definitions were included for clarity: (a) clients: recipients of health care may include individuals, families, communities, and populations from any race, ethnicity or ancestry, culture, or religious background. The term clients is used throughout the *Essentials* document to reflect the focus of nursing care; (b) services: the delivery of genetic and genomic health care; (c) resources: genetic and genomic tools and sites for healthcare referrals for delivery of nursing care; (d) technology: the use of tools or machines to perform tasks, in this case the identification and assessment of genetic and genomic information (e.g., the use of microarray technology to assess the genetic features of a specific tumor); and (e) pedigree: a graphic illustration of a family health history using standardized symbols (Bennett et al., 1995).

After much discussion, the essential competencies agreed upon through consensus were approved by the representatives at the September 2005 meeting with the plan to send the

final document to all nursing organizations for endorsement. The essential competencies (Table 2) apply to all registered nurses, with the expectation that competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills. Table 3 shows the professional nursing organizations that have endorsed the *Essentials* document. Nursing organizations through endorsement of this document have agreed with the content and will also support and promote initiatives within their own organizations to implement the competencies. Because research advances will necessitate frequent revisiting of competency expectations, the term of endorsement is 5 years. Unsolicited endorsement from two schools of nursing has also been received. Additionally, two groups concerned about consumer health have provided recognition of the importance of genetic and genomic nursing competency through their endorsement of this document. Updates of endorsing organizations can be retrieved from <http://www.nursingworld.org/ethics/genetics>. A monograph version of the *Essentials* document is also available (A limited number of print copies are available from NHGRI, NIH Bldg 31 Rm. 4B09 Bethesda, MD 20892–2152 or the electronic file can be accessed at <http://www.genome.gov/17517037> or <http://www.nursingworld.org/ethics/genetics>).

Despite extensive efforts, not all professional nursing organizations responded to our request for consideration of genetic and genomics nursing competency document review. Others declined to endorse the document citing reasons such as “not considered a priority for members,” “insufficient time to devote to this subject,” and “insufficient resources.” With time, planning, and dedicated resources, all professional nurses should become aware of the importance of these competencies for them and their constituency.

Next Steps

Now that consensus has been achieved regarding the importance of genetic and genomic nursing competency, the next step is to formulate a strategic action plan. The ultimate goal is to make the *Essentials* a living document that brings new life into the integration of genetic and genomic competency throughout education, practice, and regulation and quality control. This is a crucial time during which plans are underway to engage the nursing community in establishing action plans for implementation. Representatives of select endorsing nursing organizations have been invited to be part of an advisory group to plan for these next steps. Through conference calls and meetings a strategic plan for implementation and outcome evaluation will be finalized.

The progress of this effort in the US has universal implications for nurses worldwide. Partnering with other disciplines and with nurses from other countries can lead to insights and opportunities not yet considered. Steps to consider efforts to improve international nursing competency in genetics and genomics will also be considered.

Conclusions

Integrating genetic and genomic information into all aspects of nursing practice requires that multiple building blocks be put in place through a multipronged strategic plan. Addressing the needs of faculty, practicing nurses, and regulatory agencies will begin to provide those building blocks to reshape the environment in which nurses learn, provide clinical care,

and demonstrate competency. This rebuilding effort will require a significant investment. Incremental and cumulative rewards of such an investment will result in optimized health care that integrates genetic and genomic information. Of utmost importance to the success of this initiative is establishing the relevance of genetics and genomics to the nursing community. To achieve these goals requires focus on research, practice, and education aimed at preparing the nursing workforce with special attention to translating genetic and genomic knowledge into practice. Nurse awareness and adoption of the competencies as outlined in the *Essentials* document is the beginning, a foundation from which to now build.

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Table 1.**Steering Committee Members**

Co-Chairs:	
Jean Jenkins, RN, PhD, FAAN	National Human Genome Research Institute, NIH
Kathleen Calzone, RN, MSN, APNG, FAAN	International Society of Nurses in Genetics National Cancer Institute, NIH
Members:	
Laurie Badzek, RN, MS, JD, LLM	American Nurses Association
Carolyn Constantin, RNC, PhD	Centers for Disease Control and Prevention
Annette Debisette, RN, DNSc, ANP	Health Resources and Services Administration
Suzanne Feetham, RN, PhD, FAAN	Health Resources and Services Administration
Denise Geolot, RN, PhD, FAAN	Health Resources and Services Administration
Pamela Hagan, RN, MSN	American Nurses Association
Madeleine Hess, RN, PhD	Health Resources and Services Administration
Dale Lea, RN, MS, MPH, CGC, APNG, FAAN	National Human Genome Research Institute, NIH
Judith Lewis, RNC, PhD, FAAN	Virginia Commonwealth University
Kerry Nesseler, RN, MS	Health Resources and Services Administration
Kathleen Potempa, RN, DNSc, FAAN	Oregon Health Sciences University
Cynthia Prows, RN, MSN	Cincinnati Children's Hospital Medical Center
Elizabeth Thomson, RN, DNSc, CGC, FAAN	National Human Genome Research Institute, NIH
Melinda Tinkle, RN, PhD	National Institute of Nursing Research, NIH
Janet Williams, RN, PhD, FAAN	University of Iowa

Table 2.

Essential Competencies	
Domain	Competencies
Professional responsibilities	<p>All registered nurses are expected to engage in professional role activities that are consistent with Nursing: Scope and Standards of Practice, 2004, American Nurses Association. In addition, competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills in order to:</p> <ul style="list-style-type: none"> • Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients. • Advocate for clients access to desired genetic/genomic services and/or resources including support groups. • Examine competency of practice on a regular basis, identifying areas of strength, as well as areas in which professional development related to genetics and genomics would be beneficial. • Incorporate genetic and genomic technologies and information into registered nurse practice. • Demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy and preferred language. • Advocate for the rights of all clients for autonomous, informed genetic and genomic-related decision-making and voluntary action.
Professional practice	<p>Nursing assessment: applying and integrating genetic and genomic knowledge</p> <p>The registered nurse:</p> <ul style="list-style-type: none"> • Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness. • Demonstrates ability to elicit a minimum of three-generation family health history. • Constructs a pedigree from collected family history information using standardized symbols and terminology. • Collects personal, health, and developmental histories that consider genetic, environmental, and genomic influences and risks. • Conducts comprehensive health and physical assessments which incorporate knowledge about genetic, environmental, and genomic influences and risk factors. • Critically analyzes the history and physical assessment findings for genetic, environmental, and genomic influences and risk factors. • Assesses clients' knowledge, perceptions, and responses to genetic and genomic information. • Develops a plan of care that incorporates genetic and genomic assessment information. <p>Identification</p> <p>The registered nurse:</p> <ul style="list-style-type: none"> • Identifies clients who may benefit from specific genetic and genomic information and/or services based on assessment data. • Identifies credible, accurate, appropriate and current genetic and genomic information, resources, services and/or technologies specific to given clients. • Identifies ethical, ethnic/ancestral, cultural, religious, legal, fiscal, and societal issues related to genetic and genomic information and technologies. • Defines issues that undermine the rights of all clients for autonomous, informed genetic and genomic-related decision-making and voluntary action. <p>Referral activities</p> <p>The registered nurse:</p>

Domain	Competencies
•	Facilitates referrals for specialized genetic and genomic services for clients as needed.
Provision of education, care, and support	
The registered nurse:	
•	Provides clients with interpretation of selective genetic and genomic information or services .
•	Provides clients with credible, accurate, appropriate and current genetic and genomic information, resources, services, and/or technologies that facilitate decision-making.
•	Uses health promotion and disease prevention practices to:
•	Considers genetic and genomic influences on personal and environmental risk factors.
•	Incorporates knowledge of genetic and/or genomic risk factors (e.g., a client with a genetic predisposition for high cholesterol who can benefit from a change in lifestyle that will decrease the likelihood that the genetic risk will be expressed) .
•	Uses genetic and genomic-based interventions and information to improve clients' outcomes.
•	Collaborates with healthcare providers in providing genetic and genomic healthcare.
•	Collaborates with insurance providers and payers to facilitate reimbursement for genetic and genomic healthcare services.
•	Performs interventions and treatments appropriate to clients' genetics and genomic healthcare needs.
•	Evaluates impact and effectiveness of genetic and genomic technology, information, interventions, and treatments on clients' outcome.

Table 3.**Endorsing Organizations**

Academy of Medical-Surgical Nurses
 Academy of Neonatal Nurses LLC
 American Academy of Ambulatory Care Nursing
 American Academy of Nursing
 American Association of Colleges of Nursing
 American Association of Neuroscience Nurses
 American Association of Occupational Health Nurses
 American Nephrology Nurses Association
 American Nurses Association
 American Nurses Credentialing Center
 American Psychiatric Nurses Association
 American Radiological Nurses Association
 American Society of Pain Management Nursing
 American Society of Plastic Surgical Nurses
 Association of Pediatric Oncology Nurses
 Association of Perioperative Registered Nurses
 Association of Women's Health, Obstetric and Neonatal Nurses
 Council of Cardiovascular Nursing of the American Heart Association
 Council of International Neonatal Nurses
 Dermatology Nurses Association
 Developmental Disabilities Nurses Association
 Genetic Alliance
 Hospice and Palliative Nurses Association
 International Society of Nurses in Genetics
 March of Dimes
 National Association of Clinical Nurse Specialists
 National Association of Hispanic Nurses
 National Association of Neonatal Nurses
 National Association of Orthopedic Nurses
 National Association of Pediatric Nurse Practitioners
 National Coalition of Ethnic Minority Nurse Associations
 National Conference of Gerontological Nurse Practitioners
 National Gerontological Nursing Association
 National League for Nursing
 National League for Nursing Accrediting Commission
 National Nursing Staff Development Organization
 National Organization of Nurse Practitioner Faculties
 Oncology Nursing Society
 Pediatric Endocrinology Nursing Society
 Philippine Nurses Association of America

Sigma Theta Tau International
Society for Vascular Nursing
Society of Pediatric Nurses
Society of Urologic Nurses and Associates
Southern Regional Education Board Council on Collegiate Education for Nursing
Endorsing schools of nursing
Johns Hopkins University School of Nursing
Nell Hodgson Woodruff School of Nursing, Emory University

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