CHAPTER 1

The Scope of Cancer Genetics and Genomics Nursing Practice

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Professional Responsibilities Domain:
- 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

(Consensus Panel on Genetic/Genomic Nursing Competencies, 2009)

INTRODUCTION

Traditionally, knowledge of genetics has been viewed as useful but not necessary to nursing practice (Prows, Glass, Nicol, Skirton, & Williams, 2005). In the 1990s, cancer genetics emerged as a medical specialty, introducing new options to identify individuals with an inherited susceptibility to cancer (Biesecker & Garber, 1995). The influence of genetics on cancer care has continued to expand with the transition into genomics, the interaction of multiple genes and the environment and how they affect cancer development, screening, diagnosis, and treatment. With the rapid translation of genetics and genomics into the clinical arena, the implications for oncology nursing are profound and have changed the scope of oncology nursing practice (Calzone, Lea, & Masny, 2006).

Evidence for the broad implications of genetics and genomics on cancer care spans the entire cancer care continuum from conception to end of life. Genetic and genomic information is being used not just to predict risk but also to increase the understanding of the biology of the disease, develop novel screening and diagnostic modalities, characterize malignancies with greater precision, establish tumor-specific treatment regimens, develop novel therapeutic modalities, and optimize medication response through the elucidation of drug metabolism. Cancer care is in the midst of a transition from traditional disease-oriented therapies to one of personalized care secondary to genetic and genomic information and technology.

The diffusion of genetics and genomics into cancer care hinges on the ability of oncology healthcare providers, including nurses, to incorporate this information and technology into their practice (Khoury et al., 2007). The science of genetics and genomics is the foundation of oncology nursing practice because at the cellular level, cancer is a complex disease consisting of multiple genetic changes (Calzone et al., 2006). Genetics and genomics practice is no longer just a specialty limited to care of the 5%–10% of individuals with an inherited susceptibility to cancer, but also influences the care provided by nurses to all individuals at risk for or affected by any form of cancer. Oncology nurses are challenged with developing and implementing nursing interventions that take into account

the influence of a person's genotype when providing care. Cancer predisposition genetic testing and tumor genotyping have become much more widespread, resulting in the availability of more tailored interventions for cancer screening, surveillance, risk reduction, and treatment.

The vast majority of oncology nurses at all levels of educational preparation have had no instruction in genetics and genomics as a basic science or preparation regarding the unique implications of genetic and genomic information (Peterson, Rieger, Marani, deMoor, & Gritz, 2001; Prows et al., 2005). As a result, oncology nurses currently are limited in their understanding of genetic and genomic concepts and their ability to incorporate genetics and genomics into their practice. Oncology nurses at both the general and advanced practice levels must be competent in a basic foundation in genetics and genomics to practice in today's oncology healthcare environment. Oncology nurses who are involved in the subspecialty of cancer genetics require extensive ongoing educational preparation, clinical experience, and credentialing by the Genetic Nursing Credentialing Commission (Cook, Kase, Middelton, & Monsen, 2003). Details of credentialing in the specialty of nursing and genetics are covered in Chapter 14.

WHAT INFLUENCES THE SCOPE OF NURSING PRACTICE?

Genetic and genomic advances applicable to oncology care have expanded the scope of oncology nursing practice and highlight the critical need for oncology nurses to have a foundational understanding of the scientific underpinning of genetics and genomics. Although nurses are bound by the scope of nursing practice as defined by the American Nurses Association (ANA), state boards of nursing, and nursing specialty organizations, few nurses understand how these documents influence their practice. Scope of nursing practice refers to the activities that an individual can perform within a specific profession, for example, whom the practitioner can treat and under what circumstances (Klein, 2007). ANA (2004) broadly defines the scope of nursing practice at the basic and advanced practice level for the entire profession. Scope of practice is further refined in the United States by individual states through each state's Nurse Practice Act, which defines the legal authority for registered nurses (RNs) and advanced practice nurses (APNs) to practice in that state. Individual state boards of nursing regulate nursing practice at the state level, define the legal requirements that must be met to practice within that state, and are responsible for enforcing the state Nurse Practice Act. Specialty organizations further refine the scope of nursing practice within a given specialty by defining additional activities that can be performed specific to that specialty. For oncology nurses, the Oncology Nursing Society defines the scope of practice (Brant & Wickham, 2004; Jacobs, 2003). For nurses practicing in genetics and genomics, the International Society of Nurses in Genetics (ISONG, 2007) defines the scope of practice. Scope and standards of specialty nursing practice in the United States are the responsibility of professional nursing organizations who use as the foundation the scope and standards of practice that apply to all nurses as defined by ANA (2004).

INTERFACING THE ONCOLOGY AND THE GENETIC AND GENOMIC SCOPES OF NURSING PRACTICE

Oncology nursing care is holistic and complex, interfacing with the scope of practice of numerous nursing specialties, especially genomics. When considering the biology of cancer, a disease that is genomic at the level of the cell, the scope of oncology nursing practice falls within the domain of the definition of genetic and genomic nursing.

> Genetics/genomics nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis of human response, and advocacy in the care of the genetic and genomic health of individuals, families, communities, and populations. This includes health issues, genetic conditions, and diseases or susceptibilities to diseases caused or influenced by genes in interaction with other risk factors that may require nursing care. (ISONG, 2007, p. 2)

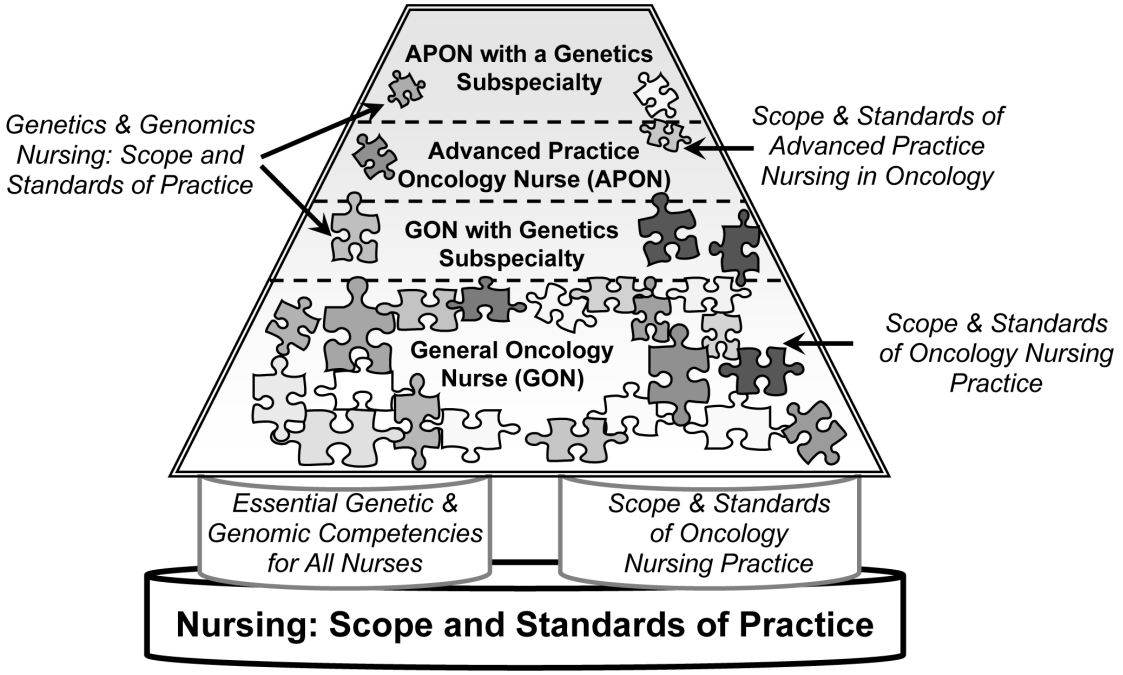
The genetics and genomics specialty is different from most other nursing specialties that interface with oncology nursing in that it affects the entire continuum of cancer care from conception to end of life (Calzone et al., 2006). The genetic and genomic influence on cancer care includes identifying at-risk individuals; using gene expression profiles to characterize disease, determine aggressiveness, and optimize therapeutic decision making; developing genetically and genomically targeted therapies; and using pharmacogenomics to more precisely predict outcomes of medications.

DIMENSIONS OF CANCER GENETIC AND GENOMIC NURSING PRACTICE

Four levels differentiate the scope of oncology nursing practice in genetics and genomics: general oncology nurses, general oncology nurses with a subspecialty in genetics, advanced practice oncology nurses, and advanced practice oncology nurses with a subspecialty in genetics (see Figure 1-1). The features that distinguish one level of practice from another include educational preparation, professional experience, practice specialty, and specific job roles and responsibilities. As an example, general oncology nurses may specialize in a particular area, such as radiation oncology or chemotherapy, and some tasks and job responsibilities may be the same as those of APNs. However, this is not equivalent to practicing at the advanced practice level, which is defined by educational preparation and overall job responsibilities.

All oncology nurses, regardless of their level of practice in genetics and genomics, are responsible for delivering care within the framework of the nursing process and the boundaries of the scope of oncology nursing practice as defined by ANA and ONS (ANA, 2004; Brant & Wickham, 2004; Jacobs, 2003). The scope of practice outlined in this chapter more clearly delineates the role of oncology nurses in cancer genetics. The cancer genetics nursing role is encompassed by the scope of practice in oncology nursing. The practice of genetics oncology nursing, as in all oncology nursing, incorporates the roles of direct caregiver, educator, consultant, administrator, and researcher. Oncology nursing practice that integrates genetics and genomics extends to all care delivery settings in which clients experiencing or at risk for developing cancer receive health care, education, and counseling for prevention, screening, early detection, treatment, and rehabilitation.

FIGURE 1-1 LEVELS OF ONCOLOGY NURSING PRACTICE IN GENETICS AND GENOMICS



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At all four practice levels, nurses incorporate theoretical knowledge of genetics and genomics into their role as direct care providers, coordinators, consultants, educators, researchers, and administrators (Middelton, Dimond, Calzone, Davis, & Jenkins, 2002). General oncology nurses and advanced practice oncology nurses use genetic and genomic information in a manner consistent with their educational preparation and the role, scope, and standards of oncology nursing as established by ONS (Brant & Wickham, 2004; Jacobs, 2003). At both levels, the genetic and genomic knowledge integrated into practice has broad applicability and limited depth. Just as all oncology nurses are expected to comprehend and incorporate into their practice the basic tenets of carcinogenesis, the same expectation is applied to cancer genetics and genomics because cancer is a genomic disease. APNs in oncology with a genetics subspecialty are prepared at the master's or doctoral level with additional training in genetics.

Scope of practice for APNs in genetics, oncology, or any other specialty depends upon basic education as a nurse combined with additional specialized training that entitles the APN to practice in areas beyond the scope of the RN. All APNs must first be trained and recognized by their state of practice with their RN license and are additionally certified in their advanced practice specialty (Klein, 2007).

INCORPORATION OF CANCER GENETICS AND GENOMICS IN VARIOUS PRACTICE SETTINGS

The incorporation of genetics and genomics into oncology nursing practice occurs in settings that encompass the entire spectrum of cancer care. This includes settings of health promotion, prevention, and detection; surgical, medical, and radiation oncology; and bone marrow transplantation. Cancer genetics and genomics is not simply a subspecialty; it is the scientific basis for understanding the process of carcinogenesis and the response of cancer to intervention. Therefore, genetics and genomics permeate all aspects of oncology nursing practice and have implications for nurses in any and all oncology practice settings. Examples of practice settings in oncology resulting from genetics and genomics advances include, but are not limited to, cancer genetics centers, laboratories offering genetic testing and tumor profiling, private industry (including clinical and biotechnology laboratories and pharmaceutical companies), and cancer genomics education programs. As genetic services continue to expand into a variety of settings, especially primary care settings, so too will genetics nursing practice.

SCOPE OF ONCOLOGY NURSING PRACTICE IN GENETICS AND GENOMICS

General Oncology Nurses

Nurses at the general level apply genetic and genomic knowledge in their practice by identifying, referring, educating, supporting, treating, and caring for clients at risk for or affected by cancer. The general oncology nurse requires knowledge of genetic and genomic principles as they relate to the assessment of cancer through screening, early-detection methods, prevention practices, and treatment. In this era of direct to consumer marketing, clients are becoming more aware of the genetic and genomic contribution to health and illness (Gray & Olopade, 2003; Wolfberg, 2006). As a consequence, general oncology nurses are addressing clients' questions about genetics and genomics as well as referring them to genetics professionals when indicated. In terms of cancer genetic and genomic practice, general oncology nurses function similar to nurses at the beginner or advanced-beginner stage (Benner, 2000). As Benner described, these stages of practice are characterized by limited practical experience in cancer genetics and genomics, functioning directed by rules and guidelines. General oncology nurses do not have the knowledge base or experience in cancer genetics and genomics to prioritize the importance of genetic and genomic information or know what to expect in certain situations regarding genetic and genomic interventions. Practice by general oncology nurses related to genetic and genomic conditions and interventions predominately focuses on the accomplishment of tasks. However, many of these tasks will have a genetic and genomic component. For example, general oncology nurses will collect family histories, educate clients on and administer genetically and genomically targeted therapies, collect biospecimens for clinical or research purposes that include evaluation of genetic or genomic information, and assess clients for medications or other substances that may affect drug metabolism that is regulated by genes such as the cytochrome P450 system. As such, general oncology nurses must achieve the basic competencies in genetics and genomics to practice in today's oncology healthcare environment (Con-

sensus Panel on Genetic/Genomic Nursing Competencies, 2009). For example, the ability to identify a client who needs a cancer genetics referral and refer them to an appropriate genetics professional is one of the core competencies.

General Oncology Nurses With a Subspecialty in Genetics

Nurses at this level are oncology nurses whose education and clinical training in genetics and genomics extends beyond that of general oncology nurses. The additional training is in the form of continuing education and experience specific to genetics and genomics or cancer genetics and genomics. However, this additional training does not fulfill the requirements for an advanced academic degree. General oncology nurses with a subspecialty in genetics and genomics are prepared to

- Perform genetics-specific assessments
- Monitor clients' and patients' status from the genetic and genomic perspective
- Educate and counsel clients about genetic and genomic issues
- Consult, collaborate with, and refer clients to other providers in the provision of genetic and genomic services.

General oncology nurses in cancer genetics and genomics have at minimum met the following criteria:

- Completion of an accredited baccalaureate program in nursing
- Continuing education in genetics
- Clinical experience as a basic genetic nurse with a greater than 50% genetic practice component.

Among the factors that distinguish general oncology genetic nursing practice from basic oncology nursing practice are expanded practice skills and knowledge in cancer genetics and genomics (ISONG, 2007).

Advanced Practice Oncology Nurses

Because advanced practice nursing requires substantial theoretical knowledge and proficient use of this knowledge in providing care, APNs understand the role of genetics and genomics in cancer care to a greater degree than do general practice nurses. Although APNs may work at the advanced practice level in oncology, in terms of genetics and genomics they may be at the beginner or advanced-beginner stage (Benner, 2000). Advanced practice oncology nurses may be faced with using theoretical knowledge uncoupled with practical experience when aspects of genetic and genomic information must be incorporated into care. Similar to general oncology nurses, when presented with an atypical case, advanced practice oncology nurses may not fully know the significance of genetic and genomic information and may not completely see the implications of a situation or know when action is needed (Benner). Nurses at both levels need genetics practitioners to help them identify what they cannot recognize. For instance, advanced practice oncology nurses may recognize that an individual with multiple primary cancers is a red flag for an inherited susceptibility to cancer. However, working with the genetic practitioner would provide expertise to determine what, if any, cancer syndrome could be associated with the individual's multiple primary cancers and whether genetic testing for a specific gene or genes is an option.

Oncology nursing practice in genetics and genomics at the advanced practice level builds on the scope of practice described for general oncology nurses. For example, advanced practice oncology nurses will interpret a family history and refer for further evaluation if indicated, educate clients and other nurses on the administration of genetically and genomically targeted therapies, interpret the results of analysis performed on biospecimens for clinical or research purposes that include evaluation of genetic or genomic information, and assess and manage clients experiencing drug toxicities that may be the result of variations in genes such as the cytochrome P450 system. As such, advanced practice oncology nurses also must achieve a basic competency in genetics and genomics to practice in today's oncology healthcare environment.

Advanced Practice Oncology Nurses With a Subspecialty in Genetics

Nurses at this level are APNs whose education and clinical training in genetics and genomics extends beyond that of advanced practice oncology nurses. The additional training in the form of an academic degree, continuing education, and experience specific to genetics and genomics or cancer genetics and genomics prepares nurses to

- Perform genetics-specific assessment and diagnosis
- Conduct a physical examination from a genetic perspective
- Develop and implement genetic and genomic–specific treatment plans
- Monitor clients' and patients' status from the genetic and genomic perspective
- Educate and counsel clients about genetic and genomic issues
- Consult, collaborate with, and refer clients to other providers in the provision of genetic and genomics services.

APNs in cancer genetics and genomics have at minimum met the following three criteria:

- Completion of an accredited graduate (masters or doctoral) program in nursing
- Completion of graduate-level genetic course work, which includes content about human, molecular, biochemical, and population genetics and genomics, technologic applications, and therapeutic modalities
- Participation in genetic and genomic clinical training supervised by any combination of the following: genetics APN, clinical geneticist, and genetic counselor.

Among the factors that distinguish advanced genetics nursing practice from basic genetics nursing practice are the complexity of decision making, leadership skills, ability to negotiate complex organizations, and expanded practice skills and knowledge in nursing and cancer genetics and genomics (ISONG, 2007). Advanced practice oncology nurses with a subspecialty in genetics and genomics:

- Ascertain which individuals, families, and populations need cancer genetic and genomic services.
- Provide and manage comprehensive care, which includes state-of-the-art cancer genetic counseling, screening, diagnosis, and therapy.
- Develop, evaluate, and improve cancer genetic and genomic services.
- Educate individuals, families, the general public, and healthcare professionals about cancer genetics and genomics.
- Assess, deliberate on, and develop recommendations about the ethical, legal, and social consequences of new and existing genetic and genomic services and technology.

Advanced practice oncology nurses with a subspecialty in genetics practice at the proficient or expert stage (Benner, 2000). At this level of practice, genetics and genomics are in-

tegrated into every aspect of oncology nursing care. Advanced practice oncology nurses with a subspecialty in genetics are able to establish the relevancy of information, rely on extensive practical knowledge from both oncology and genetics and genomics, and in specific clinical situations, understand the significance of the client's history, grasp the current situation, and modify plans in response to events. The skills of advanced practice oncology nurses with a subspecialty in genetics include, but are not limited to, those described in Table 1-1.

TABLE 1-1 Scope of Oncology Nursing Practice in Genetics: Advanced Practice Oncology Nurse With a Subspecialty in Genetics

Role	Competency
Direct care	• Conducts an in-depth personal and family assessment based on personal, medical, occupational, environmental, and family risk factors • Performs an assessment based on prior understanding of genetic conditions and practical knowledge of what ordinarily would be expected • Constructs a detailed pedigree expanded to the degree of reliable information but a minimum of three generations, including confirmation with medical records • Establishes the relevancy of genetic information • In collaboration with the cancer genetics healthcare team, uses genetic assessment data to contribute to the diagnosis of genetic risk or illness for the client and his or her family • Evaluates eligibility for genetic testing or therapeutics • Provides genetic counseling, which enhances voluntary and autonomous decision making • Provides the education necessary for informed consent for genetic testing or therapeutics • Remains sensitive to the ability of individuals and families to receive and understand genetic information • Evaluates and monitors the impact of genetic conditions, therapeutics, or testing on the client and his or her extended family and intervenes as needed • Identifies events typical of a suspected or actual genetic condition or situation and modifies the nursing plan in response to these events • Responds to the needs of the client and his or her extended family • Provides psychological support to the client and his or her extended family and facilitates successful adaptive responses
Coordinator	• Coordinates and initiates the cancer genetics healthcare team's plan, including submission of genetic samples for testing, interpretation of test results, and delivery of results to the client and his or her family • Administers and/or supervises the administration of genetic therapeutics
Consultant	• Provides consultative cancer genetic expertise to staff, the client, and the client's extended family
Educator	• Conducts an assessment of the learning and psychosocial needs of the client and his or her immediate family regarding genetic services and responds to needs that are both identified and anticipated • Delivers genetic counseling services, answers complex genetic questions, and addresses concerns • Develops further interventions based on typical expectations in regard to the suspected or actual genetic condition and the current situation • Evaluates psychosocial and physical responses to genetic testing, diagnosis, and treatment • Integrates the evaluation of responses into all aspects of care
Researcher	• Coordinates genetic clinical trials and uses research findings in care implementation • Participates in the development of cancer genetic research trials
Administrator	• Develops and monitors cancer genetic programs and services

Note. Based on information from Calzone et al., 2002.

SUMMARY

Regardless of their practice setting, oncology nurses have a role in the delivery of genetic and genomic services and the management of genetic information. All nurses at every level of academic preparation, role, or clinical specialty require genetic and genomic knowledge to identify, refer, support, and care for individuals at risk for or affected by cancer (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). Because lack of competence in a particular area by definition excludes it from a nurse's scope of practice (Klein, 2007), proficiency in the core competencies in genetics and genomics is critical for oncology nurses. A foundation in genetics and genomics currently is considered an essential part of baccalaureate nursing education in the United States (American Association of Colleges of Nursing, 2008), and the scope of this requirement has expanded with the publication of this latest edition of the *Essentials of Baccalaureate Education for Professional Nursing Practice*.

Genetics and genomics offer oncology nurses the opportunity to utilize new knowledge and technologies to improve health outcomes. Oncology nurses need to understand the biologic, ethical, and psychosocial impact of genetics and genomics on their nursing practice in order to effectively serve individuals, families, and communities in such areas as determining if a client is a carrier of a cancer-predisposing gene mutation, providing risk-based cancer screening, and administering standard cancer therapy or individualized pharmacogenomic therapy. The four phases of translating research into practice require that nurses appropriately and adequately integrate human genome variables into health care (Khoury et al., 2007). Oncology nurses are pivotal providers of quality healthcare services and are at the front line of closing the gap between research discoveries that are efficacious to cancer care and their successful adoption to optimize health.

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