

Genetics Nursing Practice Enters a New Era With Credentialing

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Abstract

In a few short years genetic nursing practice has been transformed from a nearly hidden specialty to a recognized specialty practice with formal recognition, publication of scope and standards of practice, and most recently the availability of credentialing for genetic nurses. All areas of nursing practice have been impacted by recent advances in genetic knowledge and technology. Nearly all diseases are now recognized to have a genetic component. Nurses now provide education to patients about hereditary risk for developing disease, counsel about the benefits and risks associated with genetic testing, and manage disease risk based on genetic information. The recent development of commercial testing for susceptibility genes, (such as the predisposition genes for breast ovarian cancer syndrome and colon cancer) have had a great impact on nursing's role in the identification and management of individuals at risk for developing many diseases. These developments have led to tremendous changes in genetic nursing practice, including the development of a credentialing process through the International Society of Nurses in Genetics, which recognizes nurses with expertise in genetics. This paper will describe the need and rationale for such a credential, the description of the credential and its development, the birth of the Genetic Nursing Credentialing Commission, a discussion of titles used in genetics, and an account of the personal experience of one nurse who successfully completed the requirements to obtain the credential, and an overview of what genetic nurses do in clinical practice.

The past several years have transformed genetic nursing practice from an all but, hidden practice to a recognized nursing specialty with a visible contribution to the genetic and overall health of individuals and families. Nurses have been involved in managing genetic information since the 1960's, when nurses provided services to children with genetic disorders and their families (1). Although in some respects the nurse's role today in managing genetic information and caring for individuals and families at risk for or diagnosed with genetic diseases or conditions is similar to this traditional role, the scope of practice is much broader and more encompassing. What has also changed, according to Forsman (2), is the amount of genetic information available and the population to which this information may be applied. We now know that genetic changes contribute to most, if not all diseases (3,4,5). Consequently, the scope of genetic knowledge application in nursing is limitless (6). "Nursing can ignore genetics no longer. The time for meaningful action is now" (7).

FROM THE 'OLD GENETICS' TO THE 'NEW GENETICS'

Traditionally genetics has been associated with childbearing

decision-making and caring for children with genetic disorders. Medical genetics has focused on the inheritance of hereditary disorders affecting only a small portion of the population. Genetics services have been primarily associated with prenatal genetic counseling, identification of pediatric disorders associated with birth defects and dysmorphism, and in some cases rare adult onset single gene disorders. Recent genetic and technological advances are helping us better understand how genetic changes impact human variation as well as the development of cancer, Alzheimer's, diabetes and other multifactorial diseases that are prevalent in adults.

The Human Genome Project, one of the most significant research endeavors of the twentieth century, deserves much of the credit for the discovery of these new applications of genetic information. Specifically, research from the Human Genome Project is providing a new and better understanding of the genetic contribution to disease, the development of targeted drug therapy (pharmacogenetics) and the development of genetic tests that identify those who may have or be at risk for genetic diseases. The result of this explosion of knowledge is a rapid paradigm shift from the

'old genetics' to the 'new genetics'. Under the 'new genetics' paradigm nearly all diseases have a genetic component. Now recognized is the fact that most common human diseases such as myocardial infarction, cancer, mental illness, diabetes, and Alzheimer disease are a result of complex interactions between a number of factors including the influence of one or more genes and a variety of environmental exposures (5).

The influence of recent genetic advances on nursing practice is especially evident in oncology. Oncology nurses practicing in cancer prevention and control apply genetic principles to their clinical practice daily. For example, they assess hereditary and non hereditary cancer risk factors, take detailed family histories and construct pedigrees, identify individuals and families at risk for hereditary cancer syndromes, make recommendations for cancer risk reduction, surveillance, and management, and when appropriate, counsel and educate about the risks and benefits of genetic testing (8, 9).

This genetic revolution and shift to the 'new genetics' has created a demand for health professionals in a number of clinical specialties who understand the genetic contribution to disease risk, the impact on disease management, and the genetic educational needs of patients and families. Nurses have risen to the challenge catapulting genetic nursing practice into a new era.

The purpose of this article is to describe the following: milestones in genetic nursing practice, titles used by genetic nurses, recent availability of credentialing for genetics nurses, genetic nursing scope of practice, and a description of experiencing the credentialing process by one of the first nurses to receive the APNG(c) credential.

CREDENTIALING: A NEW MILESTONE IN GENETICS NURSING PRACTICE

Genetics nursing practice has seen several memorable milestones in less than five years (see Figure 1). In the past, there has been minimal recognition of the important role that nurses can play in genetics. The International Society of Nurses in Genetics (ISONG) has clearly been the leader in working with nursing leaders to promote genetic nursing practice and develop a credentialing process for genetic nurses (10). Through these efforts, only five years ago the American Nurses Association established genetics nursing as an official specialty of nursing practice. This statement was followed by the publication of the scope and standards of clinical genetics nursing practice by the American Nurses

Association (ANA) and the International Society of Nurses in Genetics (ISONG) (11). Although determining credentialing standards is not an easy process, ISONG recognized that genetic nurses needed to have credentialing to establish competency, and a credentialing committee was formed in 1999 (12).

Figure 1: Genetics Nursing Practice Milestones

- 1960s Nurses publishing about the nurse's role in genetics and conducting genetics research
- 1984 Genetics Nursing Network was formed which later became ISONG
- 1988 International Society of Nurses in Genetics (ISONG) was incorporated
- 1997 Genetics Nursing designated an official nursing specialty by American Nurses Association
- 1998 Statement on the Scope and Standards of Genetics Clinical Nursing Practice Published by ISONG and ANA
- 2001 ISONG approved formation the Genetic Nursing Credentialing Commission (GNCC)
- 2001 Credentialing of the first Genetics Advanced Practice Nurses APNG(c)
- 2002 GNCC goes online at <http://www.geneticnurse.com>, develops a logo and becomes incorporated
- 2002 GCN credential is first offered by GNCC

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Achieving credentialing of nurses in genetics is a milestone in nursing history. When the first advanced practice nurses in genetics received the APNG(c) credential at ISONG's annual education conference in October of 2001, years of effort working toward the credentialing of genetic nurses came to fruition. Credentialing is based on submitting a portfolio of accomplishments documenting the nurse's genetic expertise (11). Standards set for the achievement of this credential are high since the nurse must also demonstrate clinical competency by submitting case histories that show the nurse's ability to apply genetic knowledge according to the scope and standards of genetics nursing practice (see Figure 3). Advanced practice nurses

interested in the APNG(c) credential must be an RN with at least a Master's in Nursing or equivalent. Additional requirements include: clinical practice experience in a genetic health setting; documentation of 50 cases where the APN has provided health care services with a genetic component; and acquisition of genetics content through classes, workshops, or continuing education units (CEUs). This credential involves submitting a portfolio demonstrating the nurse's accomplishments and competency.

Figure 2: A PNG(c) Credentialing Requirements include:

- RN with a master's in nursing or equivalent
- At least 3 years experience as a genetic nurse with 50% genetic practice component
- Documentation of 50 cases providing genetic health care in past 5 years
- 4 in depth genetic case histories reflecting ISONG standards of genetic nursing practice
- Minimum of 50 contact hours of genetic content in the past 5 years
- Three professional letters of reference

<http://www.geneticnurse.org>

In January 2002 the Genetics Nursing Credentialing Commission (GNCC) signed incorporation papers to separate from ISONG and become a separate organization to oversee the credentialing of nurses in genetics. A demand for recognition and credentialing of nurses at the baccalaureate level led to the creation of the Genetics Clinical Nurse (GCN(c)) credential, which is offered for the first time in 2002. Requirements for the GCN are similar in format to the APNG(c) and are also based on the ISONG scope and standards of nursing practice (see 4). Information about genetics nursing credentials offered by GNCC can be found at <http://www.geneticnurse.org>. For both the APNG(c) and the GCN(c), there is a fee to obtain the application packet and an additional fee to apply for the credential. In addition to the criteria listed in figures 4&5, additional requirements include but may not be limited to: performance verification from an employer, supervisor, or professional colleague, three letters of reference, evidence of research utilization and documentation of patient education.

Figure 3: GCN(c) Credentialing Requirements include:

- RN with a baccalaureate in nursing or equivalent
- 5 years experience in a genetic health setting with at least 50% of time providing genetic health services
- Documentation of 50 cases providing genetic health care within past 5 years
- 4 in depth genetic case studies reflecting ISONG standards of genetic nursing practice
- Minimum 45 contact hours of genetic content the past 5 years
- 3 professional letters of reference

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TITLING FOR GENETICS NURSES

Genetic nursing practice includes nurses at all practice levels. APNG(c), which stands for advanced practice nurse in genetics, is an official title granted by the Genetic Nursing Credentialing Commission (GNCC) to APNs in genetics who apply for and receive the APNG(c) credential. GCN(c), or genetic clinical nurse, is an official title granted by the GNCC for nurses with a bachelors degree who apply for and receive the GCN(c) credential. Nurse Geneticist is a term used by some nurses who have a doctorate with either a major or minor in genetics. The doctoral degree may be in genetics, nursing, or a related field but includes formal education in genetics at the doctoral level. CGC is an official term used by genetic counselors and is also used by some nurses who have passed the certification exam for genetic counselors offered by the American Board of Genetic Counseling (ABGC). Current requirements to sit for that exam require the candidate to have graduated from an ABGC accredited masters program in genetic counseling. In the past, however, nurses who met certain criteria were allowed to sit for this exam without having a masters in genetic counseling. Some nurses with a CGC title, however, have a masters in genetic counseling in addition to their nursing degree.

It is important to distinguish the title “genetic counselor” from the service of providing genetic counseling because they are not identical. Because genetic counselors do not currently have published standards and scope of practice, genetic counseling as a profession is often confused with genetic counseling as a clinical service. Not all genetic counselors are functioning in roles where they provide

genetic counseling, and their scope of practice is broader than just genetic counseling. Genetic counseling as a clinical service is “a short-term educational counseling process for individuals and families who have a genetic disease or who are at risk for such a disease. Genetic counseling provides patients with information about their condition and helps them make informed decisions” (National Human Genome Research Institute web site

http://www.nhgri.nih.gov/DIR/VIP/Glossary/pub_glossary.cgi?key=genetic%20counseling&view_value_pair=on downloaded February 21, 2002). Providing genetic counseling in the context of providing information to individuals and families about genetic diseases or conditions is a part of clinical practice for a variety of health care professionals, including physicians in a number of specialties, advanced practice nurses, medical geneticists (both MD and PhD), and genetic counselors.

EXPERIENCING THE PROCESS OF GENETIC CREDENTIALING – A PERSONAL VIEW

The second author (S. Mahon) has worked in the area of cancer control with an emphasis on cancer prevention, detection, and risk assessment since 1988. The availability of commercial testing for cancer susceptibility genes has dramatically changed the second author's practice as an advance practice oncology nurse. Up until this time, the second author had confined her practice to risk assessment and development of plans for cancer prevention and detection. The discovery of BRCA1 and BRCA2 in the 1990's, two genes associated with a strong predisposition to developing breast and/or ovarian cancer, and the subsequent development of genetic testing for these and other cancer susceptibility genes, has had a tremendous impact on oncology nursing practice. Approximately 7 to 10% of breast and ovarian cancer can be attributed to germline mutations inherited from a parent and mutations in BRCA1 and BRCA2 account for about 84% of these germline mutations (13). Similar testing is available for detecting mutations associated with a wide variety of hereditary cancer syndromes, including common syndromes nurse are likely to encounter such as Hereditary Nonpolyposis Colorectal Cancer (HNPCC) (5). Commercial availability of these genetic tests makes them more readily available to the general public and carries the risk that they will be ordered for persons who do not fully understand the risks and limitations of these tests. Like many other nurses, the second author was expected to provide genetic services including genetic risk assessment, genetic counseling, and management of patients with positive genetic test results.

The medical director at her institution wanted an advance practice nurse with a background in both oncology and genetics to provide a variety of services in the clinic. He wanted a comprehensive risk assessment of both hereditary and non hereditary risk factors with construction and evaluation of a pedigree. He also wanted families to receive genetic counseling and recommendations for cancer surveillance and risk reduction regardless of whether or not they pursued genetic testing. The credentialing process helped provide some validation of the appropriateness of this APN's ability to provide these genetic services. .

The second author was fortunate enough to be one of the first 13 APNs to receive the APNG(c) credential presented by ISONG last October. The decision to pursue the credential was a relatively easy one for this APN. In clinical practice she routinely provided cancer genetics education to housestaff, patients and families. The second author has been certified as an Advance Practice Oncology Nurse (AOCN®) for several years. Applying for credentialing as a genetic nurse can be very rewarding, although different than sitting down and taking an examination. Credentialing is time-consuming and takes a tremendous amount of organization to gather all of the necessary documents. Going through the process, however, forced this nurse to think about her practice. She had to consider if she was actually obtaining enough continuing education to stay well-informed in an ever-changing field. How does she follow and document nursing actions while providing education about genetics? How is patient and family education documented? What assurances are there that patient education is provided in a consistent and comprehensive way, and yet it meets the individual needs of the patient and family? Does the chart and its documentation reflect care that meets and exceeds the standards of ISONG and other organizations with statements about genetic practice? While completing the application packet for the credential, one must reflect upon these and many other questions. The credentialing process can help identify gaps in practice and may ultimately improve practice when these gaps are closed.

The ISONG/ANA Statement on the Scope and Standards of Genetics Clinical Nursing Practice (3) provides much direction when preparing the credential portfolio. This document contains both Standards of Care that relate to client management issues and Standards of Professional Performance that relate to how the nurses interact and represent themselves to the public, the profession of nursing and other health professionals. A close examination of these

Standards reveals that they are a detailed description of what nurses do daily in many different types of clinical practice especially as the standards relate to assessment, diagnosis, health promotion, patient and family education, and psychosocial support.

What should a nurse do, who wants to consider applying for the credential? After examining the credential portfolio requirements, it would probably be best to gather the materials prospectively (see figure 4). The materials can be collected retrospectively, but it probably requires more effort. Areas where it may be difficult to gather sufficient materials may relate to having 50 cases to evaluate. It is much easier to evaluate the cases as one cares for the patient than retrospectively. If the material is gathered in a prospective manner, the nurse may also identify gaps in practice that need to be addressed. As the portfolio is prepared, the nurse must think about how each chart relates to genetic nursing practice. Each chart should show evidence of a detailed family tree, other risk factors for cancer, and recommendations for prevention and detection. Some charts will have documentation about many other facets of genetic practice including psychosocial support, teaching about genetic testing and referrals to other appropriate subspecialists. The process of gathering these cases for the portfolio made it clearer about how much genetics is a part of everyday oncology nursing practice.

Another important component relates to having adequate and current professional education. This includes not only obtaining sealed transcripts, but also adequate proof of continuing education appropriate to genetics. Nurses should constantly be looking for and participating in educational opportunities related to genetics. In the world of cancer genetics there are web-based options, continuing education programs through local and national professional organizations, and other self-study programs.

Documentation of professional activities is also easier gathered prospectively. When presenting to a public group or a professional group, it is important to keep copies of the flyer or brochure announcing the talk, outlines, handouts, or other material relating to the program. Newsletter articles, patient education materials, or professional publications related to genetics written by the nurse should also be kept. Many nurses would probably be amazed by the volume of materials they have in this component of the portfolio.

The credentialing process also examines professional accountability. Nurses must demonstrate that they provide

patient and public education, as well as obtain professional education related to genetics. The credentialing process helps demonstrate to the public how well nurses provide this education and support to the public. Nurses should consider the credentialing process as one that will help advance their practice both at the individual level and for the profession.

Figure : Tips For Preparing Your Portfolio

- Plan ahead and gather the materials you need in advance
- Obtain a copy of the ISONG/ANA Statement on the Scope and Standards of Genetics Clinical Nursing Practice (available at <http://nursingworld.org/anp/pdescr.cfm?CNum=15>)
- Keep a log of your clinical hours and case studies as you go rather than try to obtain the information retrospectively
- Keep a record of your professional activities including brochures from conferences attended and materials from courses taken
- Keep copies of hand-outs from presentations you give, brochures or hand-outs you create, and articles or other materials you write
- Keep a record of honors, awards, and recognitions you receive
- Contact GNCC (<http://www.geneticnurse.org>) and ask to speak to someone who has been through the credentialing process and read the FAQ section of the GNCC web page, written by an APNG(c)

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WHAT DO GENETICS NURSES DO?

All nurses have a role in the delivery of genetics services and the management of genetic information. Nurses require genetic knowledge to identify, refer, support, and care for persons affected by or at risk for genetic conditions (10). “Genetic nursing is a holistic practice that includes assessing, planning, implementing, and evaluating the physical, spiritual, ethical, and psychosocial aspects of patients and families who have genetic concerns” (14, p.246). Genetics nurses practice in many different environments. Genetic nursing practice includes but is not

limited to the following activities: client and family assessment to identify genetic risk factors and intervention, information, service, and referral needs, take a detailed family history and construct a pedigree, analyze the assessment data, provide genetic education, and develop and carry out a plan of care to address genetic concerns (10). In addition, APNs in genetics provide genetic counseling, order and interpret genetic tests if within their scope of practice, and provide surveillance and management of persons affected by or at risk for genetic conditions (9). Figure 5 provides an overview of genetic nursing activities.

In oncology for example, areas of responsibility begin with risk assessments for cancer in patients and family members. This assessment includes a detailed family history, construction of a pedigree, and assessment of hereditary, environmental and lifestyle cancer risk factors (12). Once these risk factors are determined, the information is interpreted to the patient. Recommendations for cancer prevention and early detection can be tailored to the specific risks identified. If genetic testing for a cancer susceptibility gene is appropriate, the individual/family should be informed about the risks and benefits associated with the test, and the potential risks and benefits associated with the screening and prevention measures. The nurse also needs to explore possible psychosocial responses to the potential outcomes of a genetic test. This education may be done individually or with several family members. If testing is pursued, results are disclosed in person. At that point a tailored plan for prevention and early detection is written and given to the family or individual. Long-term follow-up includes assessment of adjustment to the test results and compliance and follow-through with the plan for cancer prevention and early detection.

Figure 5: What Do Genetic Nurses Do?

- Take detailed family histories and construct pedigrees
- Assess hereditary & nonhereditary risk factors
- Interpret the pedigree & identify genetic conditions or genetic predisposition to disease
- Provide genetic information to individuals/families
- Provide genetic counseling (APNG)
- Interpret genetic tests & laboratory data (some

APNs can order genetic tests)

- Manage and care for patients & families at risk for or affected by genetic diseases or diseases with a genetic component

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SUMMARY

Nurses have entered a new era where the reality of genetic advances and knowledge impacts the practice of every nurse. No longer is it acceptable to just mention genetics in the nursing curriculum. Understanding the contribution of genetic factors to the development of disease is fundamental to the practice of every nurse. Genetic nursing practice has been transformed from a nearly hidden specialty to a recognized specialty practice with formal recognition by ANA, publication of scope and standards of practice, and most recently the availability of credentialing for genetic nurses.

The APGN(c) and GCN(c) credentialing process offers a way to validate to both the public and other professionals, that a particular nurse has demonstrated a certain level of expertise in knowledge and clinical practice in the discipline of genetics. The genetics credentialing process offers one means for nurses to validate a readiness to assume the responsibility for this newly expanded role. The future of genetic technology is here with genetic testing, gene therapy, pharmacogenetics, genetic selection and other challenges to nursing practice. Is each and every nurse ready to address the needs of patients and families in this era of genetic information? Nurses are already creating new roles, integrating genetics into existing practice, and addressing the clinical, ethical and practice challenges the 'new genetics' has brought to the profession of nursing.

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