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Nursing Advocacy in a Post-Genomic Age

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Synopsis

The Human Genome Project will change how health is defined and how disease is prevented, diagnosed and treated. As the largest group of health care providers in contact with patients nurses need to be competent in the science of genetics. Beyond this nurses need to understand the complexities that arise in genomic health care. Ethical, legal and social issues are integral to the delivery of genomic health care and nurses must have an astute understanding of such complexities. What it means to know, to reason and to act in this post-genomic age is explored.

Keywords

ethics; genetics; genomics; nursing advocacy; nursing competencies

Nursing and genetics

The study of genetics and genomics is increasingly considered an essential science for all areas of health care ¹, requiring skill in risk assessment, genetic testing, diagnosis, targeted prevention strategies, pharmacogenomics, and genetic therapies ². While nurses must be knowledgeable of the science of genetics and have skills to engage patients, they must also understand the complexities that may arise for individuals and families. This ability to reason beyond just the clinical science and consider the wider implications of genomic health care will allow the nurse to be a true patient advocate. To reason may mean assisting the patient and family in understanding the ramifications of a genetic diagnosis, communicate the meaning of a test result, and empathize with the potential implications of new genetic knowledge. In addition, practicing in this era also requires an ethical sensitivity to the new issues raised by genomic health care.

Like most health care professionals, nurses are faced with a wealth of new information on genetics in disease and health. The average age of nurses in the U.S. is 47 years and 41% of RN's are 50 years or older with only 8% under the age of 30 years ³. It is quite likely that the majority of RN's have received little if any genetics education since the completion of the first phase of the Human Genome Project in 2003. The Human Genome Project was a successful international effort to sequence and map the entire human genome.⁴ Professional nursing and medical organizations have attempted to address this need. The International Society of Nurses in Genetics (ISONG) was incorporated in 1988 with 83 members ⁵ and now has over 400

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members from 14 countries. The role of this organization is to foster the scientific and professional growth of nurses in human genetics and genomics worldwide ⁶.

In 1995, the American Nurses Association (ANA) addressed the issue of the nurse's role in managing genetic information discussing informed consent, truth-telling, confidentiality and non-discrimination ⁷. In 1996 the American Medical Association (AMA), the ANA and the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH) formed the collaborative "organization of organizations" committed to promoting health care professional education in human genetics, the National Coalition for Health Professional Education in Genetics (NCHPEG)⁸.

In 2004 in the U.S., an effort was begun by NHGRI and the National Cancer Institute (NCI) to establish the essential nursing competencies for genetics and genomics. This effort resulted in a list of essential competencies applying to all registered nurses, "with the expectation that competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills (p.12)"⁹. The recent update of *The Essentials of Baccalaureate Education for Professional Nursing Practice* by the American Association of Colleges of Nursing (AACN)¹⁰ recommends that genomic content be included in nursing curriculum as one of the foundational sciences, in areas of clinical prevention and population health, as an area for continuous self-evaluation and life-long learning and as a component of Bachelor of Science Generalist Nursing curriculum.

One example of a nursing organization that has embraced the importance of genetics to practice is the Oncology Nursing Society (ONS). ONS offers online updates, regional classes and position statements relative to genetics (<http://www.ons.org/>). As the specialty of oncology has moved ahead in prediction, diagnosis and treatment of cancers by implementing genetic testing, tumor marker testing, and chemotherapy designed specifically for the tumor type, oncology nurses have stayed abreast of these genetic developments.

Efforts at nursing education in genetics are not limited to the United States. For example, in 2004, the International Council of Nurses published a monograph on various topics of importance about genetics in nursing and described the activities of nurses in genetics in several countries ¹¹.

In looking at nursing's role in the implementation and advancement of patient care in the era of genomic health care the topics of this special issue will be addressed: "What do nurses need to know about genetics?" "What does it mean to reason relative to genetics?" and "When to act and what to do?" While a significant number of RN's are updating this knowledge of genetics and genomics, it must be argued that knowledge of both the science and broader ethical, legal, and social issues is essential in this post-genomic age ⁵. This discussion will be organized to address the general categories of knowing, reasoning, and acting as conceptualized in this special issue. Each of these categories will be used as an exemplar of how nursing and genetics come together in practice.

What to know

Knowledge is the basis of understanding and in nursing the foundation of practice. Knowledge begins with basic understanding of terminology. Although these are complex concepts, in this article genetics is defined as the study of individual genes and their impact on relatively rare single gene disorders. Genomics is defined as the study of all the genes in the human genome together, including their interactions with each other, the environment, and the influence of other psychosocial and cultural factors ¹².

Knowledge of genetics and genomics includes understanding the implications of its significance in patient's lives, thus the meaning of genomics in health is a critical aspect of nursing practice. With any disease mechanism it is important for nurses to have knowledge of the underlying physiologic and molecular processes for such a foundation forms the basis of clinical reasoning. Understanding the genetic component of diseases requires knowledge of fundamental genetic science⁸. Examples of basic genetic information would include:

- Genetics at the molecular level: DNA and RNA replication, types of mutations etc.
- Genetics behind human diversity: Definition of polymorphism and understanding of how small gene changes impact diversity
- Types of genetic disorders: Single gene and complex disorders
- Interactions of the environment and genetic expression: Finding genetic factors that influence the risks for diabetes, cancer, high blood pressure, and other common disorders.
- Types of genetic testing: Carrier, prenatal, newborn, presymptomatic, and diagnostic, and
- Prevention and treatment of genetic diseases: Gene therapies, pharmacogenomics, targeted treatments¹³

These examples of expected nursing competency correspond to the knowledge, understanding, and expertise needed by nurses in a post-genomic age. Practicing in this era also requires an ethical sensitivity to the new issues raised by genomic health care.

How to reason

Integral to competent nursing practice is the ability to go beyond scientific knowledge of the field of genomics and examine the larger implications of genomics in healthcare. It is critical that nurses understand the ethical, legal and social implications that arise when genomics becomes part of health care practice. From the early start of the Human Genome Project, leaders in the field understood the importance of genetic advances and the impact on individuals, families, communities and cultures, and society¹⁴. Scholars continue to explore issues such as discrimination based on genetic risk, ownership of DNA, patenting of genes, and informed consent as a greater understanding of the role of genes in health is discovered.¹⁵ Examples of how nurses can employ critical thinking and reasoning skills in prenatal, diagnostic and presymptomatic genetic testing are discussed below.

Prenatal genetic testing

Most nurses are familiar with prenatal genetics as nursing curricula have typically addressed topics such as chromosomal anomalies, metabolic disorders and environmental mutagens (e.g. thalidomide). However, as knowledge of genetic mutations and associated disease risks increase, what may be less understood are the growing implications of prenatal genetic testing. Over 1600 disease associated mutations have been identified (<http://www.genetests.org/>) providing information about the risk for and/or diagnosis of a given disease.

While most people agree that adults may decide to have genetic testing to evaluate their risk for passing on a potentially harmful mutation to their offspring, the disability community and others have raised questions about an expansion of prenatal testing¹⁶. This difficult area was examined by a group of professionals interested in disability issues and lay persons impacted by disabilities who were organized by the Hastings Center, a bioethics think tank¹⁶. The disability community's critique of prenatal testing asserts: 1) prenatal genetic testing followed by selective abortion is morally problematic and 2) that the choice of prenatal genetic testing

followed by abortion is driven by misinformation. While a consensus on all issues raised by the disability community was not reached, an endorsement was given to the recommendation to reform how prenatal genetic testing information is communicated to prospective parents. Rather than have prenatal genetic test information and consent be part of the “routine” first post-conception visit and become somewhat trivialized, the recommendation is to provide more time with the intent of making prenatal genetic testing more thoughtful and considered. For example, if prenatal genetic testing is discussed in the same visit and with the same emphasis as gestational diabetes testing, the parent(s) may not understand all the ramifications of prenatal genetic testing. The disability community also recommended that when parents face the birth of a child with a potential disability they be given information of what life is like with such a child and not have the spoken or unspoken medical recommendation be termination of the pregnancy.

The role of nurses in obtaining informed consent prior to a prenatal genetic test is a critical time of interaction with the prospective parent(s). This discussion must include the benefits and risks for the parent(s) and offspring, the decisions that will be present in the face of a genetic test that indicates risk of disease/disability, the potential for a result that leaves uncertainty to the degree of risk for the offspring, and the recognition that connecting genetic test results (genotype) indicating potential disease with actual symptoms (phenotype) of the disease is not yet possible in most cases. Whether the prospective parent(s) accept or decline prenatal genetic testing and/or termination it is important that nurses put aside their personal values in the face of such difficult decisions and provide accurate and sensitive information to their patients.

Diagnostic genetic testing

Diagnostic genetic testing is typically done after symptoms of a given disease have been found. If a disease has a genetic basis the implication is that the family is at risk. Nurses have always been aware that while an individual may be affected by the condition, families are the unit of care. Such awareness is critical when genomics is part of the individual's condition. Research on young women who carry a genetic mutation for hereditary breast and ovarian cancer (HBOC) illustrates the importance of understanding how the family is impacted by genetic risk^{17, 18}. This quote from a 28 year old woman illustrates how a diagnosis of breast cancer and a genetic test showing a mutation in the BRCA1 gene impacts not only her but her sisters and her parents:

I have three sisters (age 21, 23, 27) they now have to worry about genetic counseling and possible testing and mammograms. I feel guilty (strangely enough) because I am the one that brought this out in the open. While not said out loud, I think it weighs heavy on my parents because “it came from them”. My family is no longer as lighthearted as we once were. Genetic discussions happen all the time. I feel like there is absolutely no escaping this disease. And I know that the chances of having to watch someone I love go through this are high and that breaks my heart.

Nurses who interact with young women who test positive for the BRCA1 or BRCA2 mutation need to appreciate that while a diagnosis of breast cancer at a young age is in itself very difficult, having a genetic mutation specific to the disease amplifies the impact and concerns well beyond that individual.

Presymptomatic genetic testing

Presymptomatic genetic testing occurs before the onset of a disease but within a family that has a history of a given disease¹². For example, an individual whose parent has Huntington disease (HD) may want to know if they too carry the gene mutation. Huntington disease is an autosomal dominant neurodegenerative disorder resulting in irreversible progressive loss of

cognitive, motor, and behavioral functioning that lasts 10-25 years after symptoms begin. Signs of the condition most commonly appear between the ages of 30 and 50, and individuals with HD lose their abilities to carry out responsibilities as wage earners, spouses, parents, and eventually the ability to care for themselves¹⁹. While professionals may think that individuals at risk for HD want to know their risk status only 5-20% of individuals at risk for HD have been tested²⁰. Nurses need to be sensitive as to why their patients at risk for an adult-onset genetic disease may not wish to be tested. In the case of HD, there is no effective treatment, individuals cannot “undo” the knowledge that they will develop this devastating disease, potential insurance discrimination, and reproductive choices may be made more difficult²¹. Also individuals may disrupt their own families by finding out they do not carry the HD mutation while their siblings are still at risk²² 23. Participants in a study talked about the losses they experienced after finding out they do not have the mutation for HD:

I also feel a sense of loss in my own family. Things changed that day (she received a negative HD test result), and I was not prepared for the loneliness that I would feel. I don't feel like the same sister that shared the fear about our futures (siblings). Now being happy for my own future seems selfish and fearing for their future seems condescending. Even with my sister that I am very close to we no longer speak of Huntington's. We use to joke around about sharing a nursing home room and now I know she keeps her feelings to herself. And I feel that any attempts to empathize will not be interpreted in the same way they use to.

Once again it is critical that nurses understand the larger implications of genetic testing. Research has shown that while most patients are appreciative of knowing they carry a mutation that increases their risk for a particular disease they also speak of a “before” and “after”. They describe their lives and that of their families as different after genetic testing and an appreciation of such an impact is critical for nurses who engage patients anywhere along the trajectory of a genetic diagnosis¹⁷ 18. Understanding the potential ripple effects in families that surround genetic testing is important. It may be the case that only one person in the family has the genetic test but by doing so, the implications of an inheritable genetic disease is brought to the foreground²⁴. Genetic disease is a family affair and nurses must be prepared to engage not only the individual patient but other family members as well.

Issues of family changes after genetic testing, including fears of future disease, and disease in siblings and offspring are inherent. Difficulty living with the knowledge of risk for a potential future disease onset, fears of discrimination and stigmatization, and wondering if the hope for genetic-based therapies is realistic are just a few examples of the worries manifested by patients. Nurses who have a sound knowledge base in the science and understand the implications of genetic information are better prepared to provide high quality care in this new arena.

When to act

Nursing is a practice discipline and so it is by actions that nurses manifest their professionalism. To act in this post-genomic age requires an awareness and appreciation for the complexities and uniqueness of genetic information. As our understanding of gene-gene and gene-environment interaction increases the complexities of disease prevention, diagnosis and prognosis will increase. Recognizing this, nurses must act with the greatest sensitivity and discretion in managing genetic information. While issues of privacy and confidentiality are always important in health care it is difficult to overstate their importance relative to genetic information of a patient. Hand-in-hand with actions protecting the privacy and confidentiality of patient information is the role of the nurse in obtaining informed consent for any procedure that requires the collection and analyzing of an individual's DNA. Patients must understand what type of information they will receive, who will have access to this information, what

happens to their DNA after the test is done and how the test results will benefit and/or potentially harm them and their family.

In 2006 a consensus panel, co-chaired by Jean Jenkins, from the NHGRI and Kathleen Calzone of the NCI published a set of essential genetic competencies that apply to all registered nurses². These competencies reflect the minimal knowledge set expected of a registered nurse. At the time of their publication, these competencies were endorsed by multiple nursing organizations including the ANA and the ANCC and two colleges of nursing. Examples of actions that nurses can take and the corresponding competency (shown in quotes) in relation to genetic information about their patients include:

- Manage genetic information
 - “Advocate for the rights of all clients for autonomous, informed genetic and genomic-related decision making and voluntary action”
- Refer a patient to genetics specialists when appropriate
 - “Facilitates referrals for specialized genetic and genomic services for clients as needed”
- Educate patients about genetics
 - “Provides clients with credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies that facilitate decision making
- Work for equal access for all patients to genetic services
 - “Advocate for clients access to desired genetic/genomic services and/or resources including support groups”

To act as a nurse means to engage in informed practice with knowledge and expertise. In genomic health care taking action and being aware of the implications of those actions is part of an ethically informed practice. To better understand how the expected competencies may be performed, examples of each action will be briefly discussed.

Manage genetic information

An early document²⁵ published by the ANA addressed the need for nurses to actively protect patients' genetic information. Professional nursing conduct as described in the nursing code of ethics²⁶ addresses protection of patient information, early in the Human Genome Project process leaders in nursing, other health care fields and bioethics²⁷ recognized that genetic information was in some ways unique. Examples given for the uniqueness of genetic information include: 1) Genetics yields vast amounts of personal data about an individual, 2) Screening and testing can give information about future health risks, 3) Screening and testing may yield information about other family members, and 4) DNA samples can be stored and analyzed in the future²⁵. To illustrate the first two points: while a blood test for cholesterol levels will tell an individual whether or not his or her level is normal, a genetic test for an alteration in the APOE gene may indicate that an individual has an exceptionally high risk for high cholesterol levels and heart disease but may also indicate a risk for Alzheimer's disease (AD)²⁸. An individual who simply wants to know if he or she is at risk for coronary artery disease (CAD) may not welcome information about risk for AD. The type and amount of data available from an individual's genome is unmatched by other medical tests. Nurses who have access to genetic information must be aware and sensitive to what it is their patient is actually seeking and not overstep by conveying more information or providing education than what is sought.

The example of APOE testing also illustrates that a genetic test may indicate that siblings, offspring and other extended family may also be at risk for CAD and AD²⁹. The United States health care system strongly supports patient autonomy, however genetic information is familial in nature and therefore complicates notions of individuals' autonomy, and thus brings new complexities to the management of health information. Questions have risen regarding whether or not health care providers are responsible for notifying family members of their patients who have tested positive for a gene mutation that significantly increases the risk for disease^{30, 31}. Research largely indicates that individuals who obtain their genetic test results will disclose this information to selected family members although it may be over a longer period of time than might be expected^{17 32-34}. Nurses must realize that genetic information often takes on a quality for the patient and family above and beyond typical medical information. Being cognizant of the patient's privacy and the confidentiality of the information is central to nursing care in this post-genomic age.

Finally, DNA may be stored and analyzed in the future, which speaks to the possibility of breeches of both privacy and informed consent if such use extends beyond that which was originally provided. The question of who "owns" the DNA sample^{35, 36 37} has been raised. A DNA sample may be stored with identifying information or may be de-identified, raising other questions such as: who has access to stored DNA, what tests may be run on the sample in the future, who retains rights of ownership of the samples and whether there is a duty to the "owner" to be kept informed of future test results. The critical job of the nurse is to be certain that the informed consent process is thorough and provides understandable information to the patient as to the purpose of the genetic test, the risks and benefits, how the results and subsequent information will be handled, what happens to the DNA sample in the future, if there is any secondary use of the genetic material, and if the patient and/or family will have access to future research discoveries in which their DNA was used^{25 2}. Nurses are often responsible for ensuring the adequacy of the informed consent procedures and it is critical that they understand the larger picture of genetic information in order to adequately advocate for their patients in this arena.

Refer a patient to genetics specialists when appropriate

One of the professional practices specifically addressed in the *Essential Nursing Competencies for Genetics and Genomics 2* is for the registered nurse to "Facilitate referrals for specialized genetic and genomic services for clients as needed" (p.12). This action requires two elements: 1) recognizing when the patient has a potential genetic condition, and 2) recognizing that the setting in which the nurse is seeing the patient is not sufficient to address the genetic concerns of that patient. Examples of an infection control RN and a Family Nurse Practitioner (FNP) in a retail health clinic will help illustrate this particular action. The first example shows the incorporation of pharmacogenetics which is the study of drug reactions based on genetic makeup. The second example indicates the renewed interest and acknowledgment of the importance of a three generation family history assessment in primary care settings.

An infection control RN, Ruth, is working in a community health clinic that manages the weekly medication administration of isoniazid for tuberculosis patients. One of Ruth's patients has been consistently complaining of numbness in his hands and feet. The dosage of isoniazid has been checked and is appropriate for the weight of this patient. Because Ruth has completed some continuing education units on pharmacogenetics and knows that drug metabolism is directed by genes she begins to suspect that her patient may be a "slow acetylator" of isoniazid due to a mutation in the genes that code for the enzyme N-acetyltransferase. Ruth recommends that her patient's acetylator status be determined and in the meantime administers pyridoxine as this drug prevents the peripheral neuropathy secondary to high serum levels of isoniazid^{38, 39}

Jeff is a FNP in a retail health clinic in a branch of a nationwide drug store. Recently the company has required as part of the intake assessment a three generation family history for cardiac diseases, cancers and diabetes. Jeff's first patient of the day is a 25 year old female in for a complaint of a sore throat. However while doing the family history it is evident that this patient's family has several occurrences of breast cancer with an onset before age 50 years. The patient tells Jeff she is aware of this but doesn't really know what to do and has not ever had a consistent primary care doctor. Because Jeff knows that certain gene mutations (BRCA1 and BRCA2) are associated with early onset breast cancer and ovarian cancer and this patient's family history indicates she may be at risk for having such mutations, he gives her information about local genetic counseling services and recommends that she follow up with a genetic counselor to have her risk evaluated.

As more genetic tests and pharmacogenetic information becomes available nurses will have to assess what they know and when appropriate refer their patients to genetic specialists.

Educate patients about genetics

Except for a few well-elucidated mutations little is actually known about what genes with any certainty predict disease. For example, though several genes have been associated with the development of type 2 diabetes none of them are predictive to any degree⁴⁰. Time Magazine's number one invention of the year in 2008⁴¹ was the company 23andMe who for \$399 will sequence an individual's genome and provide a picture of disease risk, ancestry and traits (<https://www.23andme.com/>). Such direct-to-consumer testing opens a host of concerns for health care providers⁴². While such information may be interesting and exciting to the layperson, nurses have the added responsibility of being able to help patient's interpret what such information means. The proliferation of genetic information that can now be purchased "over the counter" is interesting but largely unspecific and for that reason not much help at present in predicting future health⁴². The science has not advanced to that point and for nurses to be able to educate their patients about what a genetic test result actually means they must be aware of the difference between commercial science information (such as 23andMe and others) and actual substantiated research results⁴³. If the Human Genome Project lives up to the health care community's expectations, individual genomes will provide information about risk for disease, health resiliency, personal pharmacogenetics, potential gene therapy for diagnosed diseases and other information⁴⁴.

Work for equal access for all patients to genetic services

In a policy statement, ISONG addresses the question of equal access to genetic services: "Nurses share with other healthcare professionals the responsibility to ensure equal access to genetic information and genomic healthcare services"⁴⁵. Employing the Code of Ethics for nurses by the International Council of Nurses⁴⁶ and the American Nurses Association²⁶ this position statement points out nurses' responsibility to initiate and promote efforts to ensure the health of the public. As genetic advances continue in disease prediction, diagnoses and treatment, it is essential that all individuals in need of such services have access to them. In the United States those with little or no health insurance may have limited opportunity to access genetic health services. ISONG recommends several actions in which nurses can engage to work toward equal access for genetic services, some of which are

- Recognize and acknowledge the role of genomics as an integral component in the promotion of the public's health and wellbeing.
- Advocate and promote the right of the individual or family to voluntarily choose or to not choose 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 genetic healthcare.
- Advocate equal access to genomic healthcare.⁴⁵

Well informed nurses can significantly impact the public discussion of access to genetic services.

One barrier to access of genetic health services in the United States was removed when President Bush signed the Genetic Information Non-discrimination Act (GINA) on May 21, 2008⁴⁷. After a 13 year battle in Congress, this federal law protects Americans against discrimination based on their genetic information when it comes to health insurance and employment. The New York Times reported in February, 2008⁴⁸ that individuals who already had symptoms of a disease and those who felt they had a significant risk for a genetic disease were deciding against genetic testing because of fears of insurance discrimination. GINA potentiates the possibility for people to take full advantage of the promise of personalized medicine without fear of discrimination.

Summary

Nurses have entered the post-genomic age as professionals expected to engage with the public and provide informed up-to-date genetic information and competencies. Along with their colleagues, they will need to continue to educate themselves in the area of genomics as they respond to the needs of their patients and families. Nursing is a practice discipline and so it is by actions that nurses manifest their professionalism. To act in this post-genomic age requires an awareness and appreciation for the complexities and uniqueness of genetic information.

As the understanding of gene-gene and gene-environment interaction increases the complexities of disease prevention, diagnosis and prognosis will increase. Recognizing this, nurses must act with the greatest sensitivity and discretion in managing genetic information. While issues of privacy and confidentiality are always important in health care it is difficult to overstate their importance relative to genetic information of a patient. Hand-in-hand with actions protecting the privacy and confidentiality of patient information is the role of the nurse in obtaining informed consent for any procedure that requires the collection and analyzing of an individual's DNA. Patients must understand what type of information they will receive, who will have access to this information, what happens to their DNA after the test is done and how the test results will benefit and/or potentially harm them and their family.

Finally, the promises of genomic healthcare will only be realized if everyone has access to the technologies and improved outcomes. Equal access to health care is a challenge in the United States. Equal access to genetic-based health care is no less so and has barriers beyond that of other health care services. Nurses have an obligation to work to remove such barriers so that all individuals who could benefit from genomic healthcare have the opportunity to do so.

Genomics will drive the health care advances throughout the 21st century. As the largest health care provider group and the provider group that interacts most closely with the patient nurses have an obligation to be knowledgeable, to reason critically and to act with skill and, sensitivity in the area of genomics. It is an exciting challenge and an opportunity for both nurses and their patients.

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