Nursing and Genetics: Are You Ready?

You may wonder what genetics has to do with your nursing practice. After all, diseases stay roughly the same, right? You still need to take family histories and develop treatment plans. You still treat people holistically, with compassion and care. These statements are all true, yet in important ways, genetics is changing the course of health care for all health professionals.

Human Genome Project

In April 2003, the Human Genome Project (HGP) was completed. This vast international undertaking, spanning 13 years, mapped all the genetic information in the human body. Among other things, researchers are using this information to better understand the relationship between genes and human health. For example, they identify abnormalities in genes that cause or contribute to disease. The more scientists learn, the more genetics will be used to diagnose, monitor and treat disease.

Genomic research is working to uncover the nature of genetic function – how genes interact with other genes – how they give and take instructions, so to speak. Research comparing the human genome with the genomes of other animals and organisms is yielding yet more genetic knowledge. As more and more information becomes known about the human genome, all health professionals will need to understand the implications of this knowledge for their practice and to be ready to incorporate further change. As Francis Collins, director of the National Human Genome Research Institute in the U.S., wrote: “In genomics research...from past experience, it would be surprising (and rather disappointing) if biological, medical and social contexts did not [italics added] change in unpredictable ways” (Collins, Green, Guttmacher, & Guyer, 2003, p. 847).

Genetics researchers claim that virtually every disease has a genetic component, whether the condition is hereditary or a response to environmental stressors. Further, they claim that every person carries at least six recessive genes, each of which has the potential to develop into disease in their descendants if their sexual partner carries the same gene. The risk is either large or small, depending on the gene involved.

Genetics and nursing

Most genetically linked diseases are not rare disorders like sickle-cell anemia or cystic fibrosis. They are cancer, heart disease, diabetes, autoimmune disorders, schizophrenia, Alzheimer’s disease, depression, etc. – debilitating conditions responsible for many, many illnesses and deaths. What nurse has not cared for clients with these diseases? “There’s hardly a clinical area that isn’t touched,” states Dr. Joan Bottorff, Professor at the University of British Columbia’s School of Nursing and researcher in the field of genetics and nursing (personal communication, July 2004).
Because all diseases have a genetic component, it is important for nurses to have at least a basic understanding of human genetics. One key concept is being able to differentiate between the hereditary and genetic components of a disease. Only a very small percentage of diseases, such as Huntington’s, are the result of simply inheriting one defective gene (or gene mutation) from a parent. Cystic fibrosis is also hereditary, but the gene mutation must be inherited from both parents.

Most diseases, however, have only a genetic component. For example, skin cancer is caused by UV exposure that damages or mutates specific genes during a person’s lifetime. As another example, it is possible to have a genetic predisposition to diabetes but not experience other factors that would combine to actually develop diabetes.

Because nurses work in a wide range of clinical settings, with individuals and families across the lifespan, they will encounter people living with genetic information and with (or at risk of developing) genetic diseases. In taking a family history, a nurse may identify clients who need further genetic services or information. The nurse is often the first person a client sees after receiving information to their clients and with (or at risk of developing) genetic diseases. In taking a family history, a nurse may identify clients who need further genetic services or information. The nurse is often the first person a client sees after receiving a diagnosis, and one who understands genetics is better equipped to counsel, console and advise the client. A nurse who understands genetics can also assess client risk and interpret genetic test results. And, as a recent random sample survey shows, Canadian nurses want to participate in providing genetic services (Bottorff, in press). They want to understand the relationship between their clients’ disease and genetics so they can convey accurate information to their clients and determine appropriate care plans based on that information.

### The asset of a nursing background

A tremendous amount of what is required to incorporate genetics in nursing practice is already part of what nurses do. Central to nursing practice are such skills as health promotion, risk reduction, client education, support, counselling, working with families and taking family histories. The fundamental skills required for such practices will not change. How and when they are applied will.

The key change – and challenge – is knowledge of genetics. Nurses are ideally placed to make valuable contributions to genetic services. A recent study showed that nurses who provide genetic services in adult onset hereditary disease consider “their nursing backgrounds to be one of [their] most valuable assets” (Bottorff et al., 2004b, p. 2). With even a basic knowledge of human genetics, nurses will have many opportunities to contribute. After all, a diagnosis of a genetic disorder is just that, a diagnosis. So much more is needed. With a basic understanding of genetics, nurses will find they can make significant contributions. Without that knowledge, nurses will be left behind. One nurse expressed her concern this way: “Every time there is something exciting and different happening in nursing, it gets taken over by another profession” (Bottorff et al., 2004a, p. 10).

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<th>Nurses apply genetic knowledge to existing skills</th>
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<td>• taking detailed family histories</td>
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### In practice

A nurse takes a family history from a client who has come to a community health clinic for digestive problems. She learns that colon cancer is prevalent in the client’s family. Because she has some knowledge of genetics, she flags the information for other health professionals and offers support and counselling to the client, advising him about his risk and discussing risk-reduction behaviours. If required, she might suggest genetic counselling.

The nurse without genetic knowledge in the example above may not recognize the significance of the client’s family history and could miss the opportunity to provide helpful information, advice and many other aspects of care planning.

This is not news to nurses specializing in fields like cancer or reproductive services; their knowledge of genetics has been acquired over many years of practice. Their expertise has grown alongside that of the field. But a nurse in a non-specialty area is less likely to have had such opportunities to advance her or his knowledge of genetics.

### Integrating genetics

Genetic profiles are being used to tailor treatment decisions. Genes are being used to treat disease (gene therapy). Soon genome-based approaches for early detection and prevention of many conditions will be commonplace.

As genetic knowledge increases, so do the ethical considerations of applying that knowledge. Policies are being developed to safeguard the privacy and confidentiality of genetic information. Also, access to the Internet means that a client’s knowledge of genetics can be great – often greater than that of health professionals, including many nurses. By the same token, sources of information may not be reliable or may
be poorly understood. As with other areas of health care, professionals must be knowledgeable about genetics to help others interpret the available information and apply it in their own context.

**Ethical concerns about use of genetic information**
- discrimination in denying employment or life insurance
- use of genetic findings as evidence in criminal proceedings
- knowing a genetic predisposition when there is no effective treatment
- genetic testing on an unborn fetus (e.g., for sex selection or genetic enhancement)
- commercialization of genetic testing

Dr. Bottorff gives an example to illustrate how not all genetic information will be useful. Researchers have identified a gene that makes a person susceptible to becoming addicted to nicotine. How helpful is this information if the person is not susceptible, given what we know about the other health effects of smoking? It is still important to counsel against smoking. Because nurses are trained to consider health and well-being holistically, they may be more inclined to think critically about genetic information as it becomes available (personal communication, July 2004).

At the moment, other health professionals are often more qualified than most nurses to assess genetic risk and interpret genetic information. However, the field of genetics is growing so quickly and includes so many disorders that doctors and genetic specialists are not able to do everything themselves. Other health professionals need to be able to contribute their specific expertise and skills to genetic services. To do that, says Dr. Bottorff, “nurses are going to need to understand the genetic basis of all kinds of disorders in order to understand the treatments that are being given, as well as to address the issues and concerns of families about what the genetic basis of their disease is all about. The families are going to have lots of questions” (personal communication, July 2004).

**The Canadian context**
As discussed previously, nurses have many skills needed in genetic services. However, for many nurses, the missing link is genetic knowledge.

**Genetic knowledge base***
- human genetics terminology
- patterns of biological inheritance and variation
- value of identifying disease-associated genetic variations
- importance of family history (three generations) in assessing predisposition to disease
- role of genetic factors in maintaining health and preventing disease
- difference between clinical diagnosis of disease and genetic predisposition
- role of behavioural, social and environmental factors to modify or influence genetics
- influence of ethnicity, culture, health beliefs and economics
- potential benefits, limitations and risks of providing genetic information
- range of genetic approaches to disease treatment
- resources available to assist clients seeking genetic information services
- components of the genetic counselling process
- indications for referral to genetic specialists, genetic testing and/or gene-based interventions
- ethical, legal and social issues related to genetic testing and recording genetic information
- history of misuse of genetic information

*Adapted from core competencies endorsed by the National Coalition for Health Professional Education in Genetics (2000).

A 2002 survey of Canadian nurses revealed that just 6.6 per cent (or 64 out of 969) had participated in seminars, workshops and non-credit courses in genetics during the previous three years (Bottorff, in press). And yet, as we saw, most nurses deal with genetic conditions every day. Whether they work in genetic services or other practice settings, most nurses feel they have important roles to play in providing genetic services but “they feel inadequately trained and lacking in confidence” (Bottorff et al., 2004b, p. 2). As one nurse commented, “you have to very much educate yourself” (Bottorff et al., 2004a, p. 9).

For several years, the nursing systems in both the U.S. and U.K. have been making significant inroads in teaching genetics to nurses and incorporating genetics into nursing practice. Significantly, in the U.K., most genetic counsellors are nurses. In the U.S., genetic counselling has developed as a specialty outside of nursing. The latter case has created some overlap and lack of clarity in nursing roles. For Canadian nurses who work in genetic services, a significant issue is their lack of related credentials. “What’s going to happen is nurses are going to lose any foothold that they have in providing genetic services just because they don’t have credentials in this area,” says Dr. Bottorff (2004a, p. 13).

In Canada, no genetics educational program available is tailored to nurses. Undergraduate and graduate nursing programs give minimal attention to the field of genetics in their curricula. The field has not been incorporated into the various clinical areas of study. There are a limited number of opportunities for professional development, most of which are geared to genetic counsellors and doctors. There are several U.S.-
based curricula available online (see list of further resources at the end of this article), but none as yet reflect the Canadian experience.

Canada’s health care system, for all its current flaws and shortcomings, has some advantages over U.S.-style health care when it comes to genetic information. For example, already in the U.S., genetic testing laboratories are marketing directly to consumers. In Canada, we mete out our health resources with public funds. As such, clients go through genetic screening and counselling to determine whether they are at risk and whether genetic testing is indicated. This triage requires health professionals who understand genetics, so they can assess the need for genetic referral. With the appropriate knowledge, nurses are well-suited to this kind of role.

Next steps
A handful of researchers and organizations in Canada are working to raise the profile of genetics in nursing. The Canadian Institutes of Health Research have funded an investigative team, led by Dr. Bottorff, to explore the implications of genetics in nursing for Canada. These leaders are striving to get nurses and administrators of schools of nursing to understand the importance of genetics in nursing practice. They are encouraging the development of summer institutes and professional development opportunities so that nurses can achieve both the competencies and the credentials they need to provide genetic services, whether in general or advanced nursing practice.

Genetic discoveries with health implications receive a great deal of public attention. Education programs of the health professions are revised at regular intervals. In addition, nursing curricula incorporating genetics already exist in the U.S. and U.K. and can be adapted to the Canadian context. These factors may provide the impetus to include genetics in nursing education and professional development programs across Canada.

Nurses are the backbone of the health care system and the number one trusted health professional in Canada. Further, nurses form the largest health discipline and work in all areas of health care (Bottorff et al., 2004a). There are many ways for Canadian nurses to effectively integrate genetics into their practice. There are also many ways for nurses to shape the delivery of genetic health care to Canadians. By adding new genetic knowledge to a strong foundation of nursing competencies, nurses can make an invaluable contribution to this emerging field.

Where can I get more information?
Review these print and online resources for more on genetics and nursing


- National Coalition for Health Professional Education in Genetics. Core competencies in genetics essential for all health-care professionals. www.nchpeg.org/eduresources/core/core.asp

- National Human Genome Research Institute. Educational resources. www.genome.gov/education

What can you do?
- Get informed, read about genetics.
- Express the need for information to supervisors, nursing schools, etc.
- Organize lunch and learn sessions at work.
- Form a study group with other interested nurses.
- Sign up for an online course in genetics.
- Consider a career as a nurse researcher in genetics.
- Lobby health policy-makers about the important roles nurses can play in this field.


Curricula and tools for learning more


• Cincinnati Children’s Hospital and Medical Center. *Genetics education program for nurses.* (includes a web-based institute) www.cincinnatichildrens.org/ed/clinical/gpnf/default.htm

• Dartmouth Medical School. *Genetics in clinical practice: A team approach.* (interactive program requires CD-ROM or high-speed Internet connection)

• Foundation for Blood Research. *Practice-based genetics curriculum for nurse educators* [The Human Genome Project: Module one, sample chapter handout]. (some modules online, minimal cost for entire curriculum) www.fbr.org/publications/gen-cur-nursedu/m1o1s4-1.html


• Oncology Nursing Society. *Genetics and cancer care: A guide for oncology nurses.* www.ons.org/clinical/PreventionDetection.shtml

• University of South Dakota School of Medicine. *Clinical genetics: A self-study guide for health care providers.* http://med.usd.edu/som/genetics/curriculum/Handspic.htm

References


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