MAHCP Career Profile

Genetic Counsellors

Submitted by
Jessica Hartley, MS, CGC
and
Kim Serfas, MSc, CCGC

You have a family history of young onset cancer or sudden cardiac-related deaths. Your son has just been diagnosed with Fragile X syndrome. You and your partner have experienced recurrent miscarriages or fertility problems. Your baby has a positive newborn screen. You have a family history of a genetic condition like Cystic Fibrosis.

What medical professionals might be able to help you?

Genetic counsellors are medical professionals that assist individuals and families in understanding the natural history of birth defects and genetic conditions. They assess the risk of recurrence or occurrence of a condition and discuss inheritance patterns. They determine available testing options, are trained to interpret test results, discuss prevention, medical management and options for prenatal diagnosis. Genetic counsellors also provide supportive counselling with sensitivity to ethnic, cultural and religious diversity and address potential ethical issues. Their aim is to help patients adapt to the psychosocial and familial issues that may arise as a result of a condition and/or family history of a condition.

Depending on the concern or reason for referral, you may interact with a genetic counsellor who has a specific area of expertise. Genetic counsellors may specialize in: prenatal genetics, pediatric or adult genetics, laboratory genetics, metabolic genetics, cardiogenetics, neurogenetics or familial cancer. Some genetic counselling sessions are uncomplicated and require only one visit. Other times, multiple sessions are needed to collect additional information, to update the family or to deal with ongoing medical and/or psychosocial problems. While the ideal would be face to face counselling session, Telehealth has been a very useful and effective tool to reach out to patients outside of major centres.

Genetic counsellors can work in a wide variety of settings and collaborate with patients and their families, as well as other healthcare providers (geneticists and other physicians, social workers, dieticians and nurses), policy-makers, patient advocacy groups and researchers. Most genetic counsellors work as a member of a health care team in traditional environments, such as university medical centers and laboratory settings. Some genetic counsellors also work in administrative capacities. Many engage in research activities related to the field of medical genetics and genetic counselling.

The average genetic counsellor's work week can involve a great mixture of responsibilities and duties. These range from fielding urgent requests for information to holding regular scheduled patient clinics to provide in-person consultations. Genetic counsellors serve as educators and resource people therefore may be involved in teaching of medical students, physicians and other health care professionals, participating in public education/support events and contributing publications to the medical literature.

Like many health care professional, genetic counsellors can work with patients and families in times of extreme stress. These types of intense interactions can contribute to feelings of burn out and compassion fatigue. It is very important for the genetic counsellor to be employed in an environment that recognizes this possibility and allows for necessary de-briefing sessions to occur.

Genetic Counsellors: Back Row (left to right) Monique LaPointe, MS, CGC; Melissa Dumouchelle, MS; Patricia (Patty) Bocangel, MSc, CCGC; Kim Serfas, MSc, CCGC; Alison Elliott, MS, CGC. Front Row (left to right) Linda Carter, RN; Shannon Chin, MSc, CCGC; Sherri Burnett, MS CGC; Jessica Hartley, MS, CGC; Claudia Carilles, MS, CGC. Absent when photo was taken: Karen MacDonald, MS.

To become a genetic counsellor requires specialized training and experience in the areas of medical genetics and counselling. This training usually includes a bachelor's degree in biological or social sciences followed by a Masters degree in genetic counselling from an accredited program. Historically, genetic counsellors have also come from other backgrounds, including having other types of Master's degrees, nursing degrees, and social work degrees.

Students accepted into genetic counselling programs typically have taken university courses in basic and advanced biology, genetics, human genetics, molecular genetics, organic chemistry, biochemistry and psychology. Their academic background is often balanced by volunteering at crisis hotlines and other counselling services, working with people who have genetic conditions, shadowing a genetic counsellor, and being involved in campus groups or community projects.

Coursework in a Masters program typically includes clinical genetics, population genetics, cytogenetics, and molecular genetics coupled with psychosocial theory, ethics and counselling techniques. Clinical placement in medical genetics centres is also an integral part of the degree requirements. There are currently three accredited genetic counselling programs in Canada and approximately thirty American programs. Our staff has both Canadian-trained and American-trained genetic counsellors which adds to the diversity of the Manitoba program.

After graduating from an accredited program, genetic counsellors in Canada are encouraged to become certified in their field. Certification is initially obtained by writing a board examination through either the Canadian Association of Genetic Counsellors (CAGC) or the American Board of Genetic Counseling (ABGC). These examinations are offered biannually/annually and focus on both the medical and psychosocial aspects the genetic counselling profession.

Like other allied health professionals, genetic counsellors are life long learners. To maintain certification they must accumulate continuing education units (CEUs). CEUs are collected by attending national/international genetics conferences approved by either the CAGC or ABGC, completing online courses, teaching, and contributing to research. Although online courses are available to keep genetic counsellors up-to-date on recent advances, they cannot replace the networking and communication opportunities available at national/international conferences, which allow genetic counsellors to share their expertise and learn from that of others.

There are more than 275 genetic counsellors in Canada, 10 of which practice in the province of Manitoba. This profession is primarily female with less than a handful of male genetic counsellors in Canada. Most genetic counsellors are employed in an urban setting. Manitoba's genetic counsellors all are affiliated with the Winnipeg Health Sciences Centre.

Over the last ten years, the number of genetic counsellors in our province has tripled! This reflects the increased availability of genetic tests and reproductive technologies as well as increased awareness about genetic testing and of the importance of family history among healthcare providers and the general public. Genetic testing is evolving to provide information about chronic complex conditions, like heart disease, diabetes and cancer. In the future, genetic counsellors may work more closely with family practitioners and other specialists outside of clinical genetics to interpret and communicate test results for complex traits to help improve the patient's health-related outcome.

There is a recent movement for genetic counsellors in Canada and the U.S. to achieve licensure to be regulated healthcare providers. This is in response to the increased demand for genetic counsellors in areas of primary and specialty medicine and expanding scopes of practice. Licensure would prevent an unqualified (or under qualified) person from calling themselves a genetic counsellor, and put at risk the well-being of the patients they serve. Currently the Canadian provinces are examining the feasibility of licensure/regulation of genetic counsellors.

Genetic counsellors help individuals or families to:

1. Comprehend the medical facts, including the diagnosis, probable course of the disorder, and the available management strategies
2. Appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives
3. Understand the benefits and limitations of options for dealing with the risk of occurrence of a genetic condition
4. Select a course of action consistent with the patients' view of risk, family goals, and ethical and religious standards
5. To adjust to the diagnosis of a disorder in an affected family member and/or the risk of recurrence of that disorder