

Résumé

Définir le rôle de l'infirmière en génétique : enquête auprès des infirmières canadiennes

**Joan L. Botorff, Mary McCullum,
Lynda G. Balneaves, Mary Jane Esplen, June Carroll,
Mary Kelly et Stephanie Kieffer**

Cette étude qualitative avait pour but de décrire le rôle de l'infirmière dans la prestation de services cliniques en génétique offerts aux adultes souffrant d'une maladie héréditaire, et de déterminer les facteurs influant sur cette sphère d'exercice au Canada. Les chercheuses ont mené des entrevues téléphoniques semi-structurées auprès de 22 infirmières réparties dans cinq provinces canadiennes, qui occupent toutes une fonction à temps plein ou partiel dans un service de génétique. Par des questions ouvertes, on a cherché à obtenir des descriptions du rôle qu'elles y jouent et des facteurs qui limitent leurs interventions. L'analyse thématique des entrevues révèle qu'en plus de la consultation génétique, les infirmières assument un large éventail de rôles et de responsabilités qui font directement appel à leurs connaissances en soins infirmiers (p. ex. évaluation du patient, promotion de la santé). À cet égard, posséder une formation en soins infirmiers, savoir travailler au sein d'une équipe multidisciplinaire et la pratique du mentorat constituent des atouts. Parmi les difficultés à surmonter, on souligne l'ambiguïté du rôle, un manque de reconnaissance du savoir-faire de l'infirmière, une offre limitée en matière de formation spécialisée en génétique, l'isolement et l'instabilité des postes en ce domaine. Les auteures formulent des recommandations à l'appui du développement de cette sphère d'exercice. Face à l'intégration de la génétique au sein du système de santé, il faudra coordonner les énergies des principales intéressées à l'échelle nationale afin d'obtenir les ressources qui permettront d'exploiter à bon escient le savoir-faire des infirmières.

Mots clés : services en génétique, formation en soins infirmiers, rôle de l'infirmière, consultation génétique

Establishing Roles in Genetic Nursing: Interviews With Canadian Nurses

**Joan L. Bottorff, Mary McCullum,
Lynda G. Balneaves, Mary Jane Esplen, June Carroll,
Mary Kelly, and Stephanie Kieffer**

The purpose of this qualitative study was to describe nurses' roles in providing clinical genetic services related to adult onset hereditary disease and factors that influence genetic nursing practice in Canada. The study involved semi-structured telephone interviews with 22 nurses from 5 Canadian provinces with full-time or part-time roles in providing genetic services. The interviews included open-ended questions to elicit descriptions of genetic nursing roles and factors that support and limit opportunities in genetic nursing practice. Thematic analysis of the transcribed interviews revealed that, in addition to genetic counselling, the nurses reported a wide range of roles and responsibilities related to the provision of genetic services that drew directly on their nursing background (e.g., patient assessment, health promotion). Factors identified as supporting genetic nursing roles included nursing background, being part of a multidisciplinary team, and receiving mentorship. Challenges in establishing roles in genetic nursing were related to role ambiguity, lack of recognition of nursing expertise, limited availability of genetics education, isolation, and instability of nursing positions. Recommendations to support the development and expansion of genetic nursing practice were identified. A coordinated national effort among all stakeholders is needed to provide the resources necessary to support the appropriate and effective use of nursing expertise as genetics is integrated into the Canadian health-care system.

Keywords: genetic services, nursing education, nurses' roles, genetic counselling

Introduction

Nurses have a long history of caring for individuals and families affected by genetic conditions. Although community health and pediatric nurses were among the first to incorporate genetic knowledge into nursing practice in Canada and other countries (Lea, Anderson, & Monsen, 1998), with recent developments in medical genetics the roles and responsibilities of all health-care providers are being redefined. For example, as a result of growing attention to the genetics of adult onset hereditary diseases (e.g., cancer, Alzheimer disease), nurses in many practice settings are more frequently called upon to address questions from patients or family members about the risk for familial diseases (Lea,

Williams, Jenkins, Jones, & Calzone, 2000; Peterson, Rieger, Marani, deMoor, & Gritz, 2001). Although anecdotal evidence suggests that nurses are taking on more specialized roles in the provision of genetic services for adult onset hereditary disease, few empirical studies describing these roles have been conducted.

International developments with regard to nursing roles in the provision of genetic services have begun to be described (Feetham, 2004). Nurses in the United States have been leaders in the development of genetic nursing. For example, American oncology nurses have acknowledged the essential role of genetics in their understanding of cancer and the provision of comprehensive patient care. Specific levels of nursing practice in cancer genetics have been described and work is ongoing to support their implementation (Oncology Nursing Society, 2000). Some nurses are establishing roles on specialized genetics multi-disciplinary teams, while others are addressing genetics in the context of primary health care (Lea, 2000; Peterson et al., 2001). Organizations such as the International Society of Nurses in Genetics (ISONG), the American Nurses Association, and the Association of Genetic Nurses and Counsellors (in the United Kingdom) have developed standards of practice for both basic and advanced nursing roles in genetic services (Association of Genetic Nurses and Counsellors Education Working Group, 2002; International Society of Nurses in Genetics and American Nurses Association, 1998; Oncology Nursing Society, 2000).

In Canada there has been limited discussion of the role of nurses in providing genetic services. While there is anecdotal evidence that nurses are already delivering genetic services, we were able to locate only one Canadian survey addressing this topic (Bottofff, Blaine, et al., 2005). Participants in this national survey included 975 nurses. The findings indicate that nurses believe they play important roles in the provision of genetic services for adult onset hereditary disease. The respondents strongly supported nursing roles related to risk assessment, providing education related to adult onset hereditary disease and genetic testing, providing supportive counselling to address emotional reactions to perceived risk, and supporting individuals and families in carrying out management plans. However, Canadian nursing organizations do not appear to have identified genetics as a priority within the scope of professional nursing practice. In addition, there are few, if any, Canadian nursing education programs or courses that focus on preparing nurses to provide genetic services.

Considering the lack of attention to nursing roles in the provision of genetic services in Canada, the purpose of this descriptive exploratory study was to describe the roles of Canadian nurses whose clinical practice involves the provision of genetic services related to adult onset heredi-

tary disease, including factors that support and limit opportunities for genetic nursing practice.

Methods

A descriptive qualitative approach was used to guide data collection and analysis (Sandelowski, 2000). Following approval by the University of British Columbia ethics review board for behavioural research, we recruited nurses who provided any kind of genetic service related to adult onset hereditary disease (e.g., education, counselling, psychological support, risk assessment, screening) to individuals, families, or communities. Notices about the study were sent to provincial centres providing genetic services, national and provincial professional nursing groups, and the Canadian Association of Genetic Counsellors (CAGC). We also placed recruitment notices on e-mail distribution lists and Web sites and in professional journals and newsletters, and we distributed invitations at relevant nursing and genetics conferences. To ensure a broad range of perspectives and to ensure that the sample was as representative as possible, we asked participants to identify other nurses who could be invited to participate in the study. We attempted to recruit nurses from all provinces, from rural and urban settings, and from a range of practice settings. Nurses who provided genetic services as a part of their job were included as well as nurses for whom it was a full-time responsibility.

Following informed consent, a semi-structured telephone interview was conducted with each participant by a trained interviewer. The interview included a series of open-ended questions designed to elicit descriptions of the nurse's current role in genetics, the context in which the role evolved, factors that supported and limited her or his nursing practice related to genetics, necessary knowledge and skills, opinions about the future of genetic nursing practice, and suggestions for genetics education programs for nurses. Participants were also asked to provide copies of their job descriptions.

The telephone interviews were audiotaped, transcribed verbatim, and checked for accuracy. The investigative team reviewed initial interviews independently and then met to reach consensus on important themes (Miles & Huberman, 1994). The identified themes were used to develop a coding framework and the data were coded using NVivo, a computer program to facilitate textual analysis. Data retrieved under each code were reviewed in detail, role descriptions were compared and contrasted, areas of agreement and disagreement were explored, and key findings were summarized incorporating representative quotations. In addition to standard procedures for protecting participant anonymity, the nurses' roles are described in broad terms only, with no reference to their institution or region.

Findings

Description of Participants

Twenty-two nurses from five Canadian provinces were interviewed (see Table 1). The sample represented a range of years of experience in nursing and in providing genetic services. Almost one third of the participants had played a role in genetic nursing for 20 years or more. Over half of the participants described adult onset hereditary disease as the primary focus of their current clinical role. The majority worked as part of a multidisciplinary team. Others who spent the majority of their time providing genetic services were in nurse educator or research positions or had been hired as coordinator or manager of a clinic providing genetic services.

<i>Age (years)</i>	Mean = 48.3 (Range 29–63)
<i>Highest level of education in nursing</i>	
Diploma	6
Bachelor's degree	13
Master's degree	3
<i>Highest level of education outside of nursing</i>	
None	13
College diploma/certificate	2
Bachelor's degree	2
Master's degree	5
<i>Genetics education (number of "yes" responses)</i>	
No formal education in genetics	9
Genetics content in undergraduate/ graduate programs	4
Continuing education programs	5
<i>Number of years of practice in nursing</i>	Mean = 23.6 (Range = 5–38)
<i>Number of years in genetic nursing</i>	Mean = 11.6 (Range = 0.5–25)
<i>Current work location (multiple responses)</i>	
Metropolitan/central city	13
Metropolitan/suburbs	4
Small/mid-sized city	1
Rural community/town	9

The nurses described a wide variety of ways in which they had moved into the role of providing genetic services. Some had been asked to set up a new genetics clinic, step into a newly created position, or accept a genetic counselling position when no MSc-trained genetic counsellor was available. In addition, nurses who were providing some genetic services (e.g., in relation to prenatal genetics) described having extended their scope of practice to meet the needs of individuals and families at risk for adult onset hereditary disease. In the absence of formal programs to support nurses in making these transitions, the mentorship of medical geneticists, physicians, nursing leaders, and members of multi-disciplinary teams was viewed as a critical factor in the development of nursing roles. The nurses reported that as they developed their genetics knowledge and skills, their responsibilities and degree of autonomy increased.

Roles and Responsibilities

The nursing roles described by participants were clustered into five focus areas representing the scope of genetic nursing practice: genetic counselling, community genetics, genetics education, clinic coordination, and genetics research. The role clusters were found across settings and included overlapping responsibilities, as shown in Table 2. The majority of the nurses reported that one of their main responsibilities was genetic counselling; this group included some nurses with the job title of genetic counsellor. In attempting to convey the unique nursing perspective brought to genetic counselling, the participants described their approach as “holistic” and “compassionate.” Although some identified limitations in their genetics knowledge, they believed that their nursing background prepared them to counsel on genetic disorders within the complexity of individual and family life:

I think that nurses are probably trained to take a psychosocial history and better assess for anxiety or depression and things like that simply because of their training.... One of the strengths of nurses is that we are able to do more of a holistic assessment...the person has a genetic disorder, but that's just the diagnosis.

Although some nurses appeared proud to be working as genetic counsellors, others were uncomfortable with this job title because it did not acknowledge their nursing skills:

Do I ignore my nursing function when I'm working as a genetic counsellor? And the answer to that is no... I have never been given the title or any acknowledgement of my nursing role in genetics.... It would be very nice if my title could reflect the nursing role...for example, Advanced Practice Nurse in Cancer Genetics, which is what I am actually doing.

Table 2 Nursing Roles by Cluster		
Role Cluster	Setting	Responsibilities
Genetic counselling (<i>n</i> = 7)	Hospital or regional clinics, general genetics or cancer genetics	Conduct genetics assessment and counselling, communicate risk information, provide screening recommendations, offer genetic testing and address related issues, provide emotional support, take health history, offer health education, coordinate care, educate professionals in genetics, coordinate clinic and perform administrative functions, coordinate research
Community genetics (<i>n</i> = 3)	Public health units	Provide genetics education, engage in health promotion, provide emotional support, assess family history, make referrals and connect patient to genetic services, coordinate follow-up care
Genetics education (<i>n</i> = 5)	Specialty clinics (e.g., adult metabolic, cancer); primary care clinic	Provide patient assessment and genetics education, provide professional genetics education, clarify risk assessment and provide follow-up counselling, facilitate support groups, engage in program planning
Clinic coordination (<i>n</i> = 4)	Specialty and general genetics clinics	Assess patient health and prepare patients for clinic visits, provide patient education and support, provide and coordinate follow-up care, coordinate referrals and team services, perform administrative functions, coordinate research
Genetics research (<i>n</i> = 3)	Centres with research programs in clinical genetics	Assist with conduct of research programs, construct pedigrees and family history, provide risk assessment, coordinate referrals, organize screening

In addition to genetic counselling, participants described a wide range of responsibilities that drew on their nursing background (e.g., patient assessment, health promotion). There was also evidence of new roles emerging for nurses. Some participants described nurse educator positions, with nurses working collaboratively alongside genetic counsellors in specialized clinical roles (e.g., in a cancer genetics program) or as part of multidisciplinary teams in specialized clinics (e.g., in a metabolic disorders clinic). One nurse working in a primary care setting described the need for genetics to be integrated into her practice so she could provide education to patients and families identified as at risk for adult onset hereditary disease. A number of participants described the potential for advanced practice nurses to provide genetic services in various clinical specialties. However, the participants identified many factors that challenged as well as supported their ability, at present and in the future, to fulfil such roles.

Factors Supporting the Development of Genetic Nursing Roles

The participants expressed enthusiasm for their work in genetics and were excited about their roles. One nurse exclaimed, "I love my job, that's for sure." Factors identified as supporting their genetic nursing roles included their nursing background, being part of a multidisciplinary team, and receiving mentorship.

Nursing background. Participants described nursing education and experience as invaluable in carrying out genetic nursing responsibilities. A nursing background equipped them to provide genetic services with an appreciation for the emotional, psychological, and social impact of disorders on individuals and families and gave them the skills to plan and manage patient care. Nursing knowledge was also cited as an asset in developing programs to provide genetic services, supporting patients' successful navigation of health-care services, and communicating effectively within multidisciplinary teams. A nursing background was also said to be helpful in genetics roles because of the positive public image of nurses: "People know what a nurse is and they've probably had some good experiences with nurses, whereas I'm not sure they really know what to expect from a genetic counsellor."

Multidisciplinary teamwork. Fifteen of the 22 nurses were members of a multidisciplinary team and another five described their work as a combination of independent and collaborative practice. Participants commented on the benefits of teamwork in terms of ready access to a broad knowledge base and the opportunity for professional collaboration and support:

Well, certainly in terms of explaining basic genetics, I can explain that to anyone probably in my sleep, but if something unusual shows up on a genetic test...that is the benefit of working in a multidisciplinary team — if you don't know the answer maybe somebody else does.

The complementary roles within the multidisciplinary team were also recognized as supporting genetic nursing practice. Nurses who acknowledged that role overlap was the reality of a team approach often spoke of its benefits: “We definitely do have overlap in all our roles...depending on how busy one person is...we're all willing to step in and help each other out, so it's very collaborative and supportive.”

Mentorship was a key factor supporting the nurses, whether they were in established genetic nursing roles or were involved in developing new roles. For example, geneticists provided the education and training in genetics that some nurses needed: “The doctor I work with is a huge mentor.... She's considered an expert in so many of these diseases.... She always takes the time to discuss things with me.” Other nurses identified mentors with diverse backgrounds. Although the nurses appreciated the mentorship they received, some lamented the fact that they did not have access to the mentorship of expert genetic nurses.

Challenges to Nurses Providing Genetic Services

All the participants discussed the more difficult aspects of their roles. Five major challenges were identified by nurses as they described their work in providing genetic services for adult onset hereditary disease: role ambiguity, lack of recognition of nursing expertise, limited genetic education, isolation, and instability of nursing positions.

Role ambiguity was a common theme for those nurses with primary responsibility for providing genetic services: “I sometimes feel like a bit of a lost discipline, kind of caught between genetic counselling and nursing”; “I would have to say I'm always working as a registered nurse. However, my primary function is genetic counselling.... Am I doing nursing or am I doing genetic counselling or am I doing both?” Some nurses expressed the belief that when nursing is removed from genetic counselling, something meaningful and significant in the role is lost. One nurse was adamant that genetic nurses with nursing degrees should not call themselves genetic counsellors. She believed the title of genetic counsellor should be reserved for those with specific credentials. This reflects the current trend to limit the title to those who have completed MSc genetic counselling programs.

Ambiguity was heightened when the title of genetic counsellor was applied inconsistently. Several nurses reported being hired into genetic counselling positions that required an MSc even though they lacked this

qualification. Another nurse's job title was modified from "community genetics counsellor" to "community genetics nurse" without any corresponding change in responsibilities. The titles that the nurses held were, therefore, not insignificant and reflected the contested nature of nursing roles in the provision of genetic services.

Nurses described territorial issues that sometimes resulted in conflict. Some related these issues to the similarity of the work done by dedicated genetic counsellors and nurses providing genetic counselling. Others believed genetic counsellors were protective of their role and did not appreciate nurses' knowledge and expertise in genetics. One nurse with 22 years of nursing experience in genetic services stated:

I don't want to paint them all [MSc-prepared genetic counsellors] with that brush, because some of the best resources for me...have been some of the people that have come out of the master's program.... But then they are coming out with that feeling that we are only nurses and getting them to work comfortably with us sometimes is difficult.... They say, "You are only a nurse...I don't feel you should be doing this."

The animosity that sometimes resulted between nurses and MSc-prepared genetic counsellors was described by one nurse as "an us and them thing" and by another as "a bit of discrimination." Interestingly, one nurse observed, "The nurses who have gone [on] to become genetic counsellors are the ones who have actually given us the most noise about it."

Lack of recognition of nursing expertise. Several nurses spoke of the challenges they faced in establishing themselves as nurses providing genetic services. One nurse compared the worlds of genetics and nursing as different cultures: "As long as you're working within that genetics world, everything's okay and they can understand, but as soon as you start introducing nursing concepts...that's where I find the understanding and tolerance breaks down." While some of the nurses believed their nursing background was "played down" or unrecognized in the delivery of genetic services, ironically their responsibilities appeared to demand a strong nursing background. One nurse boldly stated, "If you are in genetics they almost presume that you are not a nurse."

One nurse sought guidance because she was concerned that providing surveillance guidelines and risk-assessment information might fall outside the scope of nursing practice: "So we did go to the College of Nurses and asked about liability and what scope of practice might be. So we did get some reassurance...[that] we are within our own boundaries."

Limited genetics education. A number of the nurses candidly acknowledged that their lack of formal education in medical genetics was

a challenge. None of the 22 participants had a degree in genetic counselling, although eight held other graduate degrees (in nursing, education, administration, and sociology). They were frustrated at the lack of specific courses in genetics and nursing programs with a genetics focus or specialty. The difficulty of keeping pace with the rapid expansion of genetics knowledge, regardless of educational background, was also highlighted. In the absence of genetics education opportunities, the nurses looked for other ways to extend their knowledge and skills:

You have to very much educate yourself. You need to get that basic knowledge that is just at the fingertips of somebody who's been through a master's program. And it's doable...you [just] have to work a little bit harder at it.

One nurse was enrolled in a PhD program but still felt she could never learn enough about genetics: "I still don't know everything I need to know about genetics...and the issue with this is — and it may sound very bitter — but I think at the end of the day I'll be a nurse who's trying to play at genetics."

Isolation. Isolation was a significant challenge for the participants. Those who worked in rural or remote settings experienced isolation from expert resources due to their geographic location. Others worked in situations where they were the only nurse on a multidisciplinary team or where they were the "specialist" in providing genetic services (e.g., community genetics nurse). A nurse who worked in a clinic described the situation:

I'd say [the] number one challenge and problem is the isolation. I work within a multidisciplinary team and everyone's fantastic...but as a nurse there's not a lot of people in the field, and I tried to establish a listserv about a year ago to share ideas and resources, but there's nobody else working in the same kind of [setting] as I do.

The lack of professional contact with nurses doing similar work hindered the participants' efforts to share knowledge and experiences with other nurses, to advocate for or organize education programs, and to build a genetics nursing specialty in Canada.

Instability of nursing positions. Without clear acknowledgement of nursing in either job titles or job qualifications, some participants believed that the specialized roles nurses had established in genetics were under threat. Several nurses stated that new genetic counselling positions had been designated as non-nursing; as a consequence nurses working in existing positions perceived themselves as a "dying breed" because future vacancies would be filled by MSc-trained genetic counsellors. One nurse who had been involved in genetics for over 30 years lamented the shift

away from nurses providing important genetic services: “Every time there’s something exciting and different happening in nursing, it gets taken over by another profession.”

Other dynamics also contributed to the perceived instability of nursing roles in genetics. In some instances, health-care restructuring or dependence on grant funding threatened nursing positions. In one region the nurses reported the closure of clinical programs in genetics and the laying off of nurses. In another region a participant feared that nursing positions in genetics would not be continued when incumbents left their jobs. In a climate of lean health-care budgets, many nurses acknowledged that funding for professional development was no longer tenable and that this adversely affected their role stability.

In other situations, nurses reported that administrators advocated for nursing positions in genetics. One nurse proudly described how the medical director of her clinic “fought” for her position when it was slated for cutting. Another nurse highlighted the importance of support from the nursing leadership in her organization: “Our program director was also a nurse who developed this whole program... As long as there’s a nurse manager we’ll be able to expand the role of nurses in genetics here.”

The potential loss of nursing involvement in genetics was viewed as disadvantageous to both nursing and genetic services. The most experienced nurse genetic counsellor among the participants spoke dramatically about the future: “I believe that we are really losing some of the core and the heart of genetic counselling by losing nurses in the field.”

Professional Membership and Certification

Professional membership and the need for certification were identified as both potential facilitators of and challenges to the establishment of nursing roles in genetics. Some nurses expressed the belief that membership in an organization such as the CAGC is immensely beneficial, while others emphasized the importance of achieving certification in genetics and still others argued that genetics nurses in Canada need their own association and certification process. Membership in the CAGC was perceived as offering opportunities for continuing education (e.g., through annual conferences) and as a means for nurses to gain the recognition they seek from the genetics community.

The advantages of certification in genetics were referred to repeatedly in the interviews. The nurses expressed the belief that without this credential they were judged as under-qualified by MSc-prepared genetic counsellors. One nurse who was certified through the CAGC examination process explained:

There was always this perception that you were doing what you were doing but you didn't have the credentials to do it.... If nurses across the country could eventually write the certification exam and pass, then obviously we have the ability.

Another nurse said that certification would enhance her confidence in providing genetic services: "I wish I had my certification because...it wouldn't help me with families, but I would be more sure of myself as far as the actual genetic information."

Although two of the seven nurses whose primary function was genetic counselling held CAGC certification, credentialing by non-nursing organizations was not the route favoured by other participants. For example, one participant was pursuing ISONG certification. Some participants expressed the view that nurses should seek to strengthen their skills and knowledge from within the nursing profession rather than look to outside associations:

I guess when I was hired into this position I thought that I needed my certification in genetic counselling. Then I sat back and thought about it, and no, I'm not getting that. I'm a registered nurse. I'm licensed and I'm going to build the genetics in nursing rather than dismiss what I have and become a certified genetic counsellor. They're different but complementary.

Recommendations by Participants

When asked to share their recommendations for expanding genetic nursing roles, most of the participants focused on education. Although most recommended that genetics content be incorporated into undergraduate nursing programs, the extent to which and manner by which this might occur were not congruent across interviews. Two nurses stated that undergraduate nursing students should learn about patterns of inheritance and develop the skills necessary to assess family history. The participants tended to see the specialty areas of nursing and postgraduate programs as the ideal intervention points for intensive genetics training. Several suggested a 1-year certificate or diploma program for nurse practitioners in genetics, or an additional specialty year, following baccalaureate nursing education, focused on genetics. Others expressed the view that the requirement for nurses should simply be master's-level training in genetic counselling. Some participants insisted on the need for nursing specialties (oncology, cardiology, pediatrics, etc.) to integrate genetics, rather than the creation of entirely new genetics-based programs. One nurse stated: "I don't see any need for us to develop a cancer genetics nursing certification program, but [we do need] to acknowledge the component of genetics within oncology nursing certification." Another nurse, referring to a successful project in the United States, recom-

mended the introduction of intensive summer programs in genetics in Canada.

When asked to predict future genetic nursing roles, almost half the participants said they believed that educating individuals and families in genetics would become a major responsibility for nurses. Other predictions offered by the participants included increasing opportunities to provide genetic services related to risk identification, taking family histories, and making referrals to connect patients with genetic resources. The participants envisioned nurses as primary care providers in genetic services and as coordinators of screening and/or case management programs. Over one third of the participants targeted genetic counselling as a nursing responsibility in the future. However, they did not agree on how the role might be recognized or credentialed. A smaller number of participants suggested that efforts should focus on nursing roles that complement rather than duplicate the responsibilities of genetic counsellors.

Discussion

This is the first study of Canadian nursing roles in genetic services for adult onset hereditary disease. The findings add to the small body of research conducted in other countries documenting emerging roles for nurses in the field of genetics. The findings reflect wide gaps in nursing education related to genetics. Many of the participants had grown with the field, entering genetics over 20 years ago, when genetic knowledge was far less developed than it is today. These nurses had accumulated vast knowledge and experience, and they recognized that other nurses would have difficulty stepping into their jobs. This concern is mirrored in a recent national survey of Canadian nurses (Bottorff, Blaine, et al., 2005). Survey findings indicate that while nurses endorse nursing roles in the provision of genetic services for adult onset hereditary disease, they lack the confidence and training necessary to fulfil these roles. The integration of genetics into health care will stimulate the further evolution of nursing roles, as well as the related development of a coherent approach to defining levels of genetic nursing practice and the preparation required for specific expanded roles. Frameworks for differentiating elementary, specialist, and advanced practice nursing roles may prove useful (Bottorff, McCullum, et al., 2005; Daly & Carnwell, 2003).

Experts claim that the absence of genetic nursing education has led to increased dependence on other disciplines (e.g., medical genetics) for genetics education, the adoption of standards of practice that are not based on nursing models of care, the undervaluing of nurses' roles in genetics, and constraints on the provision of primary care by nurses

(Anderson, 1996; Jenkins, 1997; Kirk, 1999). The findings of our research provide some support for these concerns. The nurses we interviewed lacked opportunities for genetics education and, without genetics credentials, were often seen as ill qualified to provide genetic services. In addition, their nursing expertise was often unrecognized in genetic service delivery. This may have been linked to their dependence on mentors from outside of nursing, because they usually worked in isolation from other nurse experts.

Nurses' educational needs related to the provision of genetic services have been linked to the absence or near absence of genetics content at all educational levels, and there have been urgent calls for changes to nursing education (Anderson, Monsen, Prows, Tinley, & Jenkins, 2000; Bottorff, McCullum, et al., 2005; Gottlieb, 1998; Kirk, 2004; Lashley, 2001; Peterson et al., 2001). Educational opportunities at the undergraduate and graduate levels are needed, to raise awareness about the implications of genetic discoveries for health care and to support nurses as they incorporate genetics into their practice. Continuing education for practising nurses and faculty members is also required. Genetic nurse scholars have pointed out that competencies to be considered for genetic nursing practice represent not an extension of professional practice but, rather, a reinterpretation of existing competencies "through a genetic lens" (Kirk, 2004). Because many of the nurses we interviewed were members of a multidisciplinary team, there may be advantages, as has been suggested elsewhere, to nurses becoming involved in inter-professional genetics education, in order to build collaborative working relationships (Jenkins, 2002; Jenkins, Dimond, & Steinberg, 2001).

The importance of integrating psychosocial and emotional support into genetic services has been acknowledged by Ontario's Provincial Advisory Committee on New Predictive Genetic Technologies (2001). The participants in our study indicated that they possessed the skills necessary to provide psychosocial support in complex family situations. Such nurses are well positioned to use their expertise to address this need. As genetic services expand and place increasing demands on the limited genetic counselling resources, there will be additional opportunities for nurses to provide the psychosocial support required by patients and families.

The role ambiguity that some participants described cannot be ignored. These nurses struggled with their nursing identity when they were providing genetic counselling and other genetic services. Jenkins (2000) suggests that role ambiguity may be a factor in the profession's reluctance to recognize genetics as integral to nursing practice. She cautions that nurses, in concert with other health-care specialists, will continue to be challenged to define genetic roles. In our study, mentor-

ship by non-nurses, professional isolation, and inconsistent job titles and qualifications appeared to contribute to the participants' lack of clarity about nursing roles. Although some participants described collegial and effective working relationships with genetic counsellors, for others the relationship was strained by perceived role overlap and inequalities. Unlike in the United Kingdom, where the majority of genetic counsellors are nurses, in Canada and the United States genetic counselling has developed as a sub-speciality outside of nursing. With the evolution of two disciplines providing genetic counselling, the need for collaboration between nursing and genetic counselling is obvious. A decade ago, nurses writing in the *Journal of Genetic Counseling* attempted to clarify the unique and complementary roles of genetic nurses and genetic counsellors (Lea, Williams, & Tinley, 1994). Currently, efforts are underway in the United States and the United Kingdom to further delineate genetic nursing roles and competencies (International Society of Nurses in Genetics, 2003; Kirk, McDonald, Longley, & Anstey, 2003). Our findings suggest that similar initiatives are urgently needed in Canada, to support genetic nursing practice and to inform other health professionals about nurses' contributions to genetic services.

Although credentialing in genetics may be one way to support nurses whose work is focused on the provision of genetic services, there was no consensus among our participants on the most effective model. Few of the participants sought or held a genetics credential. However, most participants were at mid- to late career and may not have had opportunities to pursue a certification process. Furthermore, beginning in 2009, nurses without an MSc in genetic counselling will be ineligible for certification through the Canadian Association of Genetic Counsellors. There will be no Canadian options to obtain a nursing genetics credential. Although some of our participants wished to have a nursing credential in genetics, none had pursued non-Canadian alternatives such as the newly developed professional portfolio evaluation process offered by the ISONG (Cook, Kase, Middelton, & Monsen, 2003). At the recent Canadian Planning Forum on Nursing in the Genomic Era, participants pointed to the urgency of establishing a process for nurses to obtain genetics credentials (Bottorff et al., 2004). Until a Canadian option is developed, nurses need assurances that non-Canadian genetics credentials will be recognized.

Interestingly, despite being Canadian pioneers in genetics nursing, our participants did not describe themselves as taking on leadership responsibilities to advance the profile of nursing in genetics. Few seemed to be aware of standards for genetic nursing practice developed in other countries and how such resources might support them in their roles. Barriers to the development of nursing leadership in genetics suggested

by our findings include a lack of resources to support networking, working across a wide range of clinical specialties associated with adult onset hereditary disease, and the instability of nursing positions. However, the passion and enthusiasm expressed by our participants suggests that there is tremendous potential to develop a strong voice for genetic nursing in Canada.

The findings of this study should be considered in light of several limitations. Despite concerted recruitment efforts, the participants may not have been fully representative of nurses who provide genetic services in Canada. Some nurses working as genetic counsellors may not have responded to our recruitment efforts targeting nurses. In addition, nurses working in specialty clinics and primary care may not have recognized the genetic component to their work. Finally, not all provinces were represented in the sample. However, the consistency of the themes expressed by the participants indicates that our findings represent the perspectives of nurses who incorporate genetics into their practice.

In summary, this study clearly indicates that nurses are providing a variety of genetic services for adult onset hereditary disease in Canada. With the continuing developments in medical genetics, it is predicted that genetics will become a part of every nurse's role in all settings (Cook, 2003; Jenkins & Collins, 2003). A coordinated national effort by professional nursing organizations, educational institutions, health-care agencies, and all levels of government is needed to support the appropriate and effective use of nurses' skills, knowledge, and expertise as genetics is integrated into the Canadian health-care system.

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Comments or queries may be directed to Joan L. Bottorff, Faculty of Health and Social Development, UBC Okanagan, 3333 University Way, Kelowna, British Columbia V1V 2B8 Canada.

Joan L. Bottorff, PhD, RN, FCAHS, is Professor and Dean, Faculty of Health and Social Development, University of British Columbia Okanagan, Kelowna, Canada. Mary McCullum, MSN, CON(C), is Nurse Educator, Hereditary Cancer Program, British Columbia Cancer Agency, Vancouver, Canada. Lynda G. Balneaves, PhD, RN, is Assistant Professor, Nursing and Health Behaviour Research Unit, School of Nursing, University of British Columbia, Vancouver. Mary Jane Esplen, PhD, RN, is Scientist and Head, Program of Psychosocial and Psychotherapy Research in Cancer Genetics, University Health Network, Toronto, Ontario, Canada. June Carroll, MD, CCFP, FCFP, is Family Physician, Mount Sinai Hospital, Toronto, and Associate Professor, Department of Family and Community Medicine, University of Toronto. Mary Kelly, MA, is Social Science Researcher, Nursing and Health Behaviour Research Unit, School of Nursing,

University of British Columbia, Vancouver. Stephanie Kieffer, MS, CGC, CCGC, is Social Science Researcher, Nursing and Health Behaviour Research Unit, School of Nursing, University of British Columbia, and Genetic Counsellor, BC Medical Genetics Program, Vancouver.