

Genetic susceptibility to cancer

Family physicians' experience

June C. Carroll, MD, CCFP, FCFP Judith Belle Brown, PhD Sean Blaine, MD, CCFP
Gord Glendon, MSC Patricia Pugh, RN Wendy Medved

ABSTRACT

OBJECTIVE To explore family physicians' experiences in dealing with genetic susceptibility to cancer.

DESIGN Qualitative study using focus groups.

SETTING Four Ontario sites: northern, rural, urban, and inner city.

PARTICIPANTS Forty rural and urban FPs participated in four focus groups: 28 were male; average age was 41.

METHOD Focus groups using a semistructured interview guide were audiotaped and transcribed. The constant comparative method of data analysis was used. Key words and concepts were identified. Data were sorted using NUD*IST software.

MAIN FINDINGS Participants realized the escalating expectations for genetic testing and its effect on family practice. They explored an expanded role for themselves in genetic testing. Possible activities included risk assessment, gatekeeping, and ordering genetic tests. They were concerned about the complexity of genetic testing, the lack of evidence regarding management, and the implications for families.

CONCLUSION We must help FPs struggling to integrate genetics into their practices, by addressing their concerns, enhancing the way they communicate information on genetics, and developing appropriate educational tools.

RÉSUMÉ

OBJECTIF Préciser l'expérience des médecins de famille (MF) qui doivent inclure la susceptibilité génétique au cancer dans leur pratique.

TYPE D'ÉTUDE Étude qualitative au moyen de groupes de discussion.

CONTEXTE Quatre endroits de l'Ontario: nord de la province, région rurale, région urbaine et quartier défavorisé.

PARTICIPANTS Quarante MF de milieux ruraux et urbains ont participé à quatre groupes de discussion : 28 d'entre eux étaient des hommes et l'âge moyen du groupe était de 41 ans.

MÉTHODE Les participants ont utilisé un guide des interviews semi-structurés et leurs discussions ont été enregistrées sur ruban magnétique, puis transcrites. L'analyse des données a été effectuée par la méthode de comparaison continue. Les mots et concepts clés ont été identifiés. Les données recueillies ont été classées à l'aide du logiciel NUD*IST.

PRINCIPAUX RÉSULTATS Les participants étaient conscients du fait que les patients ont de plus en plus d'attentes en ce qui concerne le dépistage génétique et que cela affecte la pratique de la médecine familiale. Ils ont exploré le rôle croissant qu'ils auraient à jouer dans le domaine des tests génétiques. Selon eux, ce rôle pourrait inclure l'évaluation des risques, le contrôle de l'accès aux tests génétiques et la prescription de ces tests. Ils se sont dits préoccupés par la complexité du dépistage génétique, le peu de données probantes concernant le suivi éventuel des patients et les répercussions sur la famille.

CONCLUSION Il faut aider les MF qui s'efforcent d'intégrer la génétique à leur pratique en répondant à leurs préoccupations, en améliorant la façon dont ils communiquent l'information sur ce sujet et en développant des outils de formation appropriés.

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The speed of scientific research in genetics has challenged society and medicine.¹ As genetic tests for some of the more common disorders are developed, their availability will increase, as will the public's demand for such tests. Genetic testing for susceptibility to breast, ovarian, or colorectal cancers are examples. Studies have shown that patients' demand for genetic testing for cancer susceptibility is high, even if these patients are at low risk.^{2,3}

There are not enough genetic counselors and geneticists to meet the demand.¹ Specialists' expertise can be better used for counseling high-risk patients rather than low-risk patients who are anxious or concerned. Hence, FPs can do a great deal of genetic risk assessment and counseling. Family physicians are ideally placed to assess the risk of familial cancers, identify and counsel those who are eligible for referral to familial cancer clinics, and discuss and plan preventive and health promotion strategies tailored to patients' risk of hereditary cancer.

While agreeing that FPs could take on this role, some authors have described barriers to their effectively offering genetic services. Barriers cited include lack of knowledge, inability to interpret probability information, low tolerance for uncertainty, not feeling responsible for genetic counseling and testing, lack of counseling skills, unfamiliarity with ethical issues, lack of time, and inadequate reimbursement.⁴⁻¹⁴ Family physicians *have* been willing to become involved in genetic carrier screening programs for cystic fibrosis¹⁵ and prenatal genetic screening, however.⁸

Drs Carroll and Blaine are Researchers with the Family Healthcare Research Unit (FHRU) in the Department of Family and Community Medicine at the University of Toronto (U of T) and with the Family Medicine Genetics Program at Mount Sinai Hospital in Toronto, Ont.

Dr Carroll, the Sydney G. Frankfort Chair in Family Medicine and an Associate Professor in the Department of Family and Community Medicine at U of T, practises in the Ray D. Wolfe Department of Family Medicine at Mount Sinai Hospital. **Dr Brown** is a Professor at the Centre for Studies in Family Medicine in the Department of Family Medicine at The University of Western Ontario in London. **Dr Blaine**, an Assistant Professor in Family and Community Medicine at U of T, practises family medicine in Stratford, Ont. **Mr Glendon**, a genetic counselor, is Programs Administrator with Cancer Care Ontario's Ontario Cancer Genetics Network. **Ms Pugh** and **Ms Medved** are research associates.

Educating FPs about hereditary cancer is an urgent issue. The first step is to assess their current experiences and attitudes in this area and their need for information. Studies in the United States and England have shown that most FPs acknowledge their role in genetic susceptibility screening and the relevance of genetic testing to primary care.^{1,10,15-17} In Canada, however, there is little research on this subject.¹⁸

The purpose of this project was to explore FPs' experiences in dealing with genetic susceptibility to cancer. We investigated their experiences in dealing with hereditary cancer; their role in this emerging area; and what education, information, and training they needed.

METHOD

We chose the qualitative technique of focus groups because there was very little literature to guide the kind of directive questioning about hereditary cancer that would be suitable for a survey.^{1,18} Focus groups would allow in-depth exploration from FPs' points of view and identify issues and concerns not previously considered. Ethics approval was obtained from the Ethics Review Boards of the University of Toronto and The University of Western Ontario.

Recruitment

Focus groups were conducted at each of four locations in northern, rural, urban, and inner-city areas representing different practices across Ontario. Local contacts (nurses, genetic counselors, physicians, and office receptionists) identified FPs in their communities who might be interested in participating. Some were identified because of a known interest in cancer or education. We attempted to involve opinion leaders and prominent physicians in these communities as well as community family physicians. Names were also sought from regional genetic clinics, hospital family medicine department chiefs, the nearest cancer centre, and local oncologists. Family physicians who saw a range of medical problems and were able to communicate in English were eligible to participate in the study. Maximum variation sampling was used to ensure heterogeneous groups that would enhance the depth and breadth of data.¹⁹ Family physicians who reflected a range of ages, experience, locations, and years in practice were chosen. Eligible physicians were sent a letter describing the study and received a follow-up telephone call seeking their participation.

Conduct of focus groups

Before attending a focus group, consent was obtained, and each physician completed a brief demographic questionnaire. A semistructured interview guide was used; it contained questions about their experiences with cancer genetics, their perceived role in this area, the effect of genetic testing on patients' lives, the societal and ethical implications, the need for information, and their thoughts about the future of genetics. Focus groups were moderated by one of the investigators (J.C. or S.B.) and observed by a research associate (P.P.). Each 1½-hour focus group was audiotaped and transcribed verbatim. After each session, researchers compared field notes and discussed the group process.

Analysis

Data analysis using the constant comparative method was carried out concurrently with data collection.¹⁹ After each focus group, four investigators reviewed the transcripts independently. Conducting a line-by-line analysis to identify key words, phrases, or concepts used by participants, investigators distinguished central issues. They then met to compare and combine their independent analyses. Emerging themes were explored and expanded during subsequent focus groups. Data collection continued until theme saturation was reached.

The next step in the analysis involved determining similarities, differences, and potential connections between key words, phrases, and concepts within and across focus groups. Categories were compared and contrasted. Those that reflected recurring similarities in the data became an organization scheme for the data. An open coding system was developed to organize the data. Data were then sorted using NUD*IST software to cross-reference material about the same topic within and among focus groups. Phrases or quotes that most accurately illustrated themes were identified. To enhance the credibility and trustworthiness of the findings, focus groups were transcribed verbatim, analysis was done by all members of the multidisciplinary team, and findings were presented to groups of FPs.²⁰

FINDINGS

Participants

Tables 1 and 2 show participants' demographic and practice characteristics.

Table 1. Demographic characteristics of respondents: *Mean age was 41.4 years, range 28 to 62 years (N = 40).*

RESPONDENT CHARACTERISTICS	N (%)
Sex	
• Male	28 (70.0)
• Female	12 (30.0)
Practice setting	
• Urban	23 (57.5)
• Rural	8 (20.0)
• Mixed urban and rural	9 (22.5)
Practice type	
• Solo	13 (32.5)
• Group	27 (67.5)
Practice description	
• Academic teaching unit	6 (15.0)
• Community teaching practice	11 (27.5)
• Some teaching responsibilities	7 (17.5)
• No teaching responsibilities	16 (40.0)

Table 2. Respondents' practice characteristics

PRACTICE CHARACTERISTICS	MEAN (RANGE)
No. of patients seen daily	30 (15-55)
No. of patients referred to familial cancer clinics in the last year	2 (0-12)
Patients who inquired about inherited cancers (estimated)	13.5% (0.5%-50%)
No. of patients who underwent cancer susceptibility genetic testing	3 (0-20)

Overview

A core theme emerging from focus group analysis was participants' realization of the escalating expectations for genetic testing and the subsequent effect on family practice. This was met with uncertainty, concern, and some anxiety as participants acknowledged inadequacies in their current role. In reevaluating their role in this emerging field of medicine, participants spoke of their need to assess and better understand the factors mediating an expanded role, such as patients' concerns and hopes about genetic testing and physicians' own professional concerns and hopes. With this knowledge, they thought they could begin to explore an expanded role in genomic medicine. Each of these themes is described in detail with relevant quotes.

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Escalating expectations for genetic testing

Central to the discussion of the genomic era's effect on family medicine were the escalating expectations for genetic testing. "They want to know what's in their genes. It's not just going to be cancer. I think it's going to be everything." According to participants, not only was genetic testing inevitable, but it also necessitated a change in FPs' role.

This is the tip of the iceberg in terms of genetic testing.... As we have more genes to screen for, it's not going to be practical to send everyone to the genetics clinic. There's going to be more pressure for us to do it.... At some stage we're going to end up having to do it.

Faced with this challenge, participants expressed a variety of feelings that included being "scared," "helpless," "anxious," and "overwhelmed."

I find the whole issue extremely scary because we're just on the cusp, and when you consider the gamut of diseases that will have a genetic basis in the future.... We're going to have to be experts in the human genome before very long. It's going to be very difficult.

Participants concluded that their current knowledge and role in genomic medicine were both inadequate.

I think the key issue is us being educated first of all. If we're well educated, I think we can pass on that information comfortably to our patients.... My patients expect me to be able to provide that service for them. They don't like being farmed out to a whole bunch of people they don't know.

Patients' concerns and hopes

Participants viewed patients' concerns as being driven by their personal and family experiences of cancer and genetic testing, the media, and their hopes and fears of the effect of genetic testing; many patients raised the issue of family history because they were concerned about cancer in their families. Questions from patients were described as a driving force for physicians to become more informed about genetic testing.

The most common scenario in my office is that people come in because they have one or two or more first- or second-degree relatives with cancer and say, "What are my chances of getting this?" And usually I don't know.

Participants also remarked that patients' awareness of genetic testing often came from the media or the Internet. "I get a lot of people who have got this stuff off the Internet who want to know, "Where can I go to get my genetic screening? Am I going to get cancer?"

They expressed awareness of their patients' hopes and fears about genetic testing. Patients often wanted genetic testing to determine their children's and family members' cancer risk.

He wanted to be screened and if he screened positive, he would want the rest of his family to be screened. It was not so much for his own sake. He's the type of person that has lived his life, but he would like to know whether his kids are at risk or not.

Participants were also cognizant of the consequences of genetic testing on patients' families.

On the one hand it's awful to be the one who tests positive, but on the other hand there's huge survival guilt for the one that actually tests negative too. I don't think anyone is unscathed in the whole family decision to test or not test.

This also raised issues of caring for one person or for the family as a whole.

You also get the secret keeping in families ... if you are treating a multigeneration [family], what do you do with information like that?... I mean do the children have a right to access the information about their parents?

While recognizing that negative genetic test results might be reassuring, participants were concerned about the anxiety generated just by considering genetic testing.

I have a woman who clearly is at high risk given her family history, and when I even approached the subject, her response was, "Why would I even want that? I know I'm going to get breast cancer. If you tell me I'm gene negative, I won't believe it anyway."

Professional concerns and hopes

In defining a new role for themselves in the area of genetic testing, FPs described how their professional experiences with genetic testing and their hopes and fears about this new technology affected how they approached genetics in their

practices. They observed that both personal and practice experiences with hereditary cancer influenced them.

I think it takes on ... not only a professional interest from the medical point of view but also personal. A lot of people have friends or family who have cancer, who have genetic cancer.

Some participants also described experiences with genetic testing that were disturbing and left them wondering about the value of predictive genetic testing.

I had a recent experience with genetic testing with Huntington's ... I personally felt this woman should not have testing. I did not feel she could deal with the information, but I had faith in the system. She wanted to pursue it, so we did. She's positive and she came back to the office, like she'd just been dropped and there's no net. Here I am with a woman [who] has a lot of psychological difficulties, and the system totally screwed up. She shouldn't have been tested.

Participants had mixed feelings about genetic testing. They were concerned about the validity of genetic testing for hereditary cancer and the lack of evidence for managing carriers or those at increased risk.

If you're going to do something which has a profound significance,... you've got to be damn sure of the validity of your advice according to the results of that test. And I don't think we're in that position right now.

They were also anxious and frustrated by the uncertainty of some genetic test results.

It's really a very difficult situation, and nobody's been able to give her reliable advice. In the end, the genetic testing was negative, but the conclusion is that we haven't identified a gene that can explain this. But that doesn't mean that there isn't a gene that would put you at great risk for a recurrence or other related cancers. That was the dilemma.

Participants also expressed frustration in trying to find a role for themselves in guiding their patients through this new field. This frustration stemmed partially from the rapidity of genetic discoveries and the demand for genetic tests in the absence of solid supporting scientific evidence.

The frustrating thing is all these tests become available so quickly and you're swept up into doing them or people are coming in and asking for certain things, and ... you don't necessarily realize all the consequences at that point. You're being swept along in this wave of newer technology.... It's really overwhelming. It's hard to know if you're doing good by ordering these tests.

Family physicians' expanded role

Participants discussed possible roles for themselves in the area of genetics. They all thought that genetic risk assessment was an important role for them and that they were likely to become gatekeepers, but they had different ideas of the extent of involvement they would have in genetics. Some physicians stated they would refer all patients at increased risk of hereditary cancer. Others thought that FPs should decide whether they had sufficient knowledge of genetics to counsel patients and order genetic tests themselves. These differing opinions were reflected in their comments.

If you order the tests and aren't able to follow up on the results, then you probably shouldn't be ordering the tests in the first place.

I think we should do the initial assessment and have the knowledge to make a decision as to whether we need more information from a counselor or we perhaps do the counseling ourselves.

Participants emphasized that predictive genetic testing provides information about an entire family, not just an individual patient. "If you test positive for a gene, then maybe that's going to have a ripple effect throughout the whole genetic tree." Thus, participants felt strongly that their role included highlighting these differences for their patients and counseling them about the effect of genetic testing.

Physicians were acutely aware of the complexity of communicating genetic information. Many noted that their role in explaining risks and probabilities was as yet undefined, but thought it was important to counsel in a balanced fashion.

Sometimes we're actually going to increase people's anxiety ... and sometimes we're going to alleviate anxiety, but I mean part of our role is to define those risks for them and help them understand what's going on ... to get more information. Getting the genetic information is part of your information-gathering process, and

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if you don't do that, then you're not using all the tools you have.

Underscoring FPs' new and expanded role in cancer genetics testing was the need for knowledge about hereditary cancer and the indications for genetic testing. "I think if we're not educated, it's a bit difficult for us to educate our patients." To address these issues, participants recommended various educational resources (Table 3).

Table 3. Types of educational information and tools requested by participating family physicians

FOR PHYSICIANS

Inventory of available genetic tests (continually updated)
Risk assessment tools
Referral guidelines
Testing guidelines
Training in communication of risk
Lists of genetics clinics and hereditary cancer clinics
Resources for psychosocial support
Genetics information hotline
Central database (for answering questions and assessing risk)

FOR PATIENTS

Information aids and pamphlets dealing with who qualifies for testing and the implications of testing (risks, benefits, meaning of test results; what to do based on results; what to do if low, moderate, or high risk)
Tools for assembling and assessing family history

FORMAT

Pamphlets
CD-ROMs
Laminated flow sheets
Website (constantly updated)

DISCUSSION

The findings of this study show how FPs, facing the escalating expectations for genetic testing, perceive an expanded role for themselves in genomic medicine. While acknowledging that their knowledge and role are currently inadequate, participants explored a wider role, influenced by patients' concerns and hopes and their own professional concerns and hopes regarding genetics.

Studies have shown that most FPs acknowledge their role in genetic susceptibility screening and the relevance of genetics to primary care.^{10,15-17} Physicians

have also expressed concern about the limitations and complexities of genetic testing^{13,21} and about their discomfort discussing genetic risk unless they are able to offer effective interventions.¹⁵

Some papers have identified FPs' role as gatekeeping.^{15,22} Findings of this study suggest that FPs would find it difficult to restrict their role to gatekeeping because their patients are likely to turn to them for information and assistance with decision making. These FPs appeared willing to expand their role and make discussion of genetic susceptibility to disease a part of their practice.

The authors of earlier studies have mentioned that FPs lack knowledge of genetics.^{10,15} They identified the need for paper- or computer-based tools for listing available genetic tests, collecting family history, identifying and calculating risk, deciding whom to refer for genetic counseling and testing, and outlining management and surveillance options. Family physicians in previous studies have also expressed the need for patient information and aids to decision making.¹⁵ Guidelines for referral to genetics clinics²³ might improve the appropriateness of referral.^{24,25} Other investigators are developing and evaluating tools for computerized recording of family history and risk assessment.¹⁵ A Hereditary Breast Cancer Information Aid (page 56) has been developed, evaluated, and disseminated in Canada for women with a family history of breast cancer.²⁶

Our study participants were willing to make genetics an integral part of family medicine. Armed with information and appropriate tools, they were prepared to give patients the information needed to make informed choices, address patients' fears, and take a patient-centred approach in the complex realm of genetics. Genetic testing highlights the importance of assuming a patient-centred approach because physicians must be aware of the hopes, fears, and expectations of patients facing the implications of genetic predictive technology.²⁷

It is clear from this study and others that a large educational effort is needed to prepare FPs for the new challenges that genetic testing for susceptibility to adult-onset diseases will bring.¹⁵ Studies show that FPs can learn the necessary genetics information and skills through appropriate educational programs.²⁸ Some have recommended that closer links be forged between family medicine and genetics departments, perhaps using genetic associates and specialist genetic nurses to conduct educational outreach visits.¹⁵ Further studies are needed in this area.

Limitations

This study was conducted in four Ontario communities, and findings might not be transferable to other locations. The fact that more than half the participating FPs had some teaching responsibilities might limit transferability of findings to those who do not teach, although it is unclear whether teaching influenced our participants' comments.

Conclusion

As the availability of genetic tests increases, it is vital to help FPs attempting to integrate genetics into their practices by addressing their concerns, enhancing their communication skills, and developing appropriate educational tools to assist them in their expanded role. ♣

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Contributors

Drs Carroll, Brown and Blaine made substantial contributions to concept and design, analysis and interpretation of data, and drafting the article. **Drs Carroll and Blaine and Ms Pugh** acquired the data. **Mr Glendon, Ms Pugh and Ms Medved** contributed to concept and design, analysis and interpretation of data, and revision of the article. All the authors gave final approval to the version to be published.

Competing interests

None declared

Correspondence to: Dr J.C. Carroll, Mount Sinai Hospital, Family Medicine Centre, 600 University Ave, Toronto, ON M5G 1X5; telephone (416) 586-5155; fax (416) 586-3175; e-mail june.carroll@utoronto.ca

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Editor's key points

- As genetic screening tests have become more available, patients are more frequently asking their physicians about them.
- This qualitative study among 40 Ontario family physicians explores their experiences and perceptions of their role in dealing with patients who have genetic susceptibility to cancer.
- Given the rapid evolution of genetic screening, participants indicated that the implications of test results (clinical significance, psychological effect, ethical considerations) are far from clear.
- These physicians thought they had several roles: evaluating genetic risk, counseling patients about testing, ordering tests, and referring patients for genetic consultation.
- They also suggested that new training programs and educational materials need to be developed to assist them with these issues.

Points de repère du rédacteur

- À mesure que la disponibilité des tests de dépistage génétique s'accroît, les patients consultent de plus en plus fréquemment leur médecin de famille à ce sujet.
- Cette étude qualitative auprès de 40 médecins de famille ontariens a permis d'explorer leur expérience et leur perception de leurs rôles face à la susceptibilité génétique au cancer.
- Étant donné l'évolution rapide de ce domaine, les médecins constatent que les implications des résultats d'un test de dépistage (signification du résultat en clinique, impact psychologique, enjeu éthique) sont loin d'être toujours évidents.
- Les médecins estiment qu'ils ont plusieurs rôles potentiels: évaluer les risques génétiques, conseiller les patients face au dépistage, prescrire les tests de dépistage et demander des consultations en génétique.
- Afin de préparer les médecins de famille à jouer ces rôles, il faudra élaborer des programmes de formation et développer du matériel éducatif pour les assister.

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