

Falling through the cracks

Women's experiences of ineligibility for genetic testing for risk of breast cancer

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abstract

OBJECTIVE To describe experiences of women seeking information about their risk of hereditary breast cancer who fail to meet strict eligibility criteria for genetic counseling and testing.

DESIGN Qualitative descriptive study.

SETTING Hereditary cancer program in western Canada.

PARTICIPANTS Women who had received notification of their ineligibility for referral for hereditary breast cancer risk assessment (n=20) and some of their referring physicians (n=10). Of 28 attempted contacts, five women had moved, one declined the invitation to participate, and two could not be interviewed because of scheduling conflicts. Ten of 20 physicians declined the invitation to participate.

METHOD In-depth, open-ended telephone interviews were conducted. Transcribed interviews were systematically analyzed to identify salient themes.

MAIN FINDINGS: Three themes emerged. The first theme, "It's always on your mind," points to the profound concern about breast cancer that underlies women's experiences in seeking genetic testing. The second theme, "A test is a test," reflects women's beliefs that the test was relatively simple and similar to other medical tests in that it would provide a definitive answer. The third theme, "Falling through the cracks," captures the experience of ineligibility. Women reacted with a range of emotional responses and were left frustrated in their search for more specific information about their personal risk for breast cancer. Although women were encouraged to contact their physicians, few did.

CONCLUSION These findings point to the psychological consequences in women who seek genetic testing for risk of breast cancer when they are told they are ineligible and they are not given adequate information and support.

résumé

OBJECTIF Décrire l'expérience de femmes qui cherchent des renseignements sur le risque de cancer héréditaire du sein et qui ne répondent pas aux critères d'admissibilité au counseling et aux épreuves génétiques.

CONCEPTION Une étude descriptive qualitative.

CONTEXTE Un programme sur le cancer héréditaire dans l'Ouest canadien.

PARTICIPANTS Des femmes ayant reçu un avis de leur inadmissibilité à subir une évaluation du risque de cancer héréditaire du sein (n=20) et certains de leurs médecins traitants (n=10). Des 28 tentatives de contact, cinq femmes avaient déménagé, une a refusé l'invitation à participer et deux n'ont pas pu être interviewées en raison d'un conflit d'horaire. Dix des 20 médecins ont décliné l'invitation à participer.

MÉTHODOLOGIE On a effectué des entrevues téléphoniques en profondeur à l'aide de questions à réponse ouverte. La transcription des entrevues a été analysée systématiquement pour identifier les thèmes saillants.

PRINCIPAUX RÉSULTATS Trois thèmes se sont dégagés. Le premier, « C'est toujours à l'esprit », fait valoir l'inquiétude profonde à propos du cancer du sein, inhérente à l'expérience des femmes qui cherchent à subir une épreuve génétique. Le deuxième thème, « Un test est un test », reflète la conviction des femmes que l'épreuve était relativement simple et semblable à d'autres tests médicaux, en ce sens qu'elle fournirait une réponse définitive. Le troisième thème, « Tomber entre les craques », capture l'expérience de l'inadmissibilité. Les femmes ont eu diverses réactions émotionnelles et ont éprouvé de la frustration dans leur quête de renseignements plus précis au sujet de leur risque personnel de cancer du sein. Même si on a incité les femmes à communiquer avec leur médecin, rares sont celles qui l'ont fait.

CONCLUSION Ces constatations font ressortir les conséquences psychologiques, chez les femmes qui cherchent à subir une épreuve génétique de dépistage des risques de cancer du sein, lorsqu'on les avise qu'elles ne sont pas admissibles, et qu'on ne leur donne pas suffisamment d'information et de soutien.

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Recent developments in DNA testing now allow women within some identified “breast cancer families” to get specific information about their risk of developing breast and ovarian cancers. Thus far two genes, BRCA1 and BRCA2, have been associated with hereditary breast cancer, which is estimated to account for 5% of those diagnosed each year with breast cancer. Algorithms have been developed to assist physicians in identifying women at high risk for hereditary breast cancer.¹

Current programs for providing information about risk and genetic testing for hereditary breast cancer are in the nascent stage of development and, as such, are offered on a limited basis. Although eligibility criteria vary between programs, genetic testing is not considered appropriate for the general population for many reasons, including low cost-effectiveness and limited knowledge about testing in low-risk families.

Surveys, however, have demonstrated great public interest in genetic testing for breast cancer risk.^{2,4} Concern has been expressed about whether existing programs can meet potential demand for genetic counseling and testing in cost-effective ways. In Canada, approximately 20 programs have been established or are under development.⁵ Demand for testing is expected to be substantial, and some programs are already overtaxed.

Based on previous surveys of interest in genetic testing, experts predict that many people at low risk will seek testing for reassurance.^{6,7} Anecdotal evidence suggests that some self- or physician referrals to cancer genetics programs emanate from women’s anxiety rather than strong family histories of breast cancer. Analysis of focus group discussions with women who have had a variety of experiences with breast cancer revealed that high levels of stress and uncertainty

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increased their interest in genetic testing.⁸ Some women believed that genetic test results would alleviate their anxiety, enhance their quality of life, and inform their health-related decisions. Women who hold such expectations and who are exceptionally anxious about breast cancer face negative outcomes, including reduced compliance with screening.⁹

To date, research efforts related to genetic testing for breast cancer risk have focused on women’s attitudes, knowledge, experiences of testing and its sequelae, and evaluation of counseling protocols.¹⁰⁻¹³ Very little is known about the experience of being “turned away” from a cancer genetic testing program and about women’s information and support needs after they learn they are ineligible. This study described experiences and needs of Canadian women who were found ineligible for genetic counseling and testing by one hereditary cancer program.

Methods

A qualitative design was used for this study because of its advantages for understanding women’s experiences.¹⁴ The study was conducted in a Canadian centre offering genetic testing for risk of cancer. Most women are referred to the program by family physicians. Although the referral process differs among centres, this program uses a triage system so that its limited genetic counseling resources can be directed toward those with histories most suggestive of hereditary breast cancer. A key component of referral and triage is a family history screening questionnaire, completed independently or with the assistance of a referring physician and forwarded to the genetics program. When women or physicians contact program staff, they are advised that eligibility for hereditary breast cancer risk assessment (**Table 1**) is determined on the basis of information from the questionnaire. Criteria are less stringent for assessment than for genetic testing; consequently, not all women who meet the criteria for assessment are offered testing.

Women who do not meet eligibility criteria for assessment receive a standard letter indicating that they will not be offered genetic counseling and testing because they do not appear to be a high risk for familial breast cancer. They are advised that their referring physicians have received letters explaining their ineligibility and describing cancer screening recommendations. The women are encouraged to follow up with their physicians.

After ethics approval was obtained, a purposive sampling strategy was used to select women who had applied to the hereditary cancer program and who had

Table 1. **Eligibility criteria for hereditary breast cancer risk assessment at the study site**

1. Patients must be one of the following
 - a woman with breast cancer diagnosed at age 35 or younger
OR
 - a woman with ovarian cancer diagnosed at age 50 or younger
OR
 - an Ashkenazic Jewish woman with breast or ovarian cancer
OR
 - a blood relative with a confirmed BRCA1 or BRCA2 mutation
OR
2. Patients must have a family history that includes at least two of the following
 - breast or ovarian cancer in at least two closely related women on one side of the family
 - cancer diagnoses at younger ages than expected in the general population (eg, premenopausal breast cancer)
 - one person with multiple primary cancers
 - a male relative with breast cancer

received notification of their ineligibility. Women were selected to represent a variety of ages and referral patterns (eg, self-referred, family physician-referred, or specialist-referred). Selection was restricted to women who could speak English and be contacted by telephone without long-distance charges.

Women were recruited in several stages as the study progressed. In this way, questions arising from the ongoing data analysis could be used to focus subsequent interviews. At the beginning of each phase of recruitment, letters of invitation were mailed to five to 10 potential participants. Follow-up telephone calls were made to further explain the study, answer questions, and determine interest in participating. We were unable to contact five women who had moved, and one woman declined the invitation to participate. Women who provided informed consent were offered the opportunity to be interviewed by telephone or in person. All women chose telephone interviews, which were conducted by the same trained interviewer. We were unable to interview two women because of difficulties in scheduling interviews. The open-ended, tape-recorded interviews (20 to 90 minutes long) included broad questions related to how women first became interested in their risk for breast cancer, how they came to consider genetic testing,

and experiences related to the process of application and notification of ineligibility.

To gain a more complete understanding of experiences related to seeking genetic counseling and testing, participating women were asked whether investigators could contact the physicians they had consulted about their breast cancer risk. All women provided the names of their physicians, and 10 of the 20 physicians agreed to participate in a short telephone interview. Time constraints, scheduling difficulties, and failure to return calls were reasons for non-participation. After providing informed consent, physicians participated in a 10- to 15-minute tape-recorded interview. Broad open-ended questions explored physicians' referral practices for genetic testing and their experiences in counseling women about breast cancer risk and genetic testing. No specific questions were asked about women who had participated in this study. Women and physicians who had questions about genetic testing for breast cancer risk were encouraged to contact the staff of the hereditary cancer program.

All interviews were transcribed verbatim and checked for accuracy. Data analysis began with the investigative team reviewing transcripts to identify possible themes and categories.¹⁵ This process continued until no new themes or categories emerged from the data. Gaps and questions arising from the analysis were used to guide subsequent data collection. A coding scheme was used to code all interviews, which were then entered into a computer file using NUD.IST, a software program designed for managing qualitative data. Data related to each theme were retrieved and further analyzed for salient attributes and relationships. Representative quotations were selected to illustrate important themes in the data.

Data analysis was facilitated through several investigator team meetings and validated through theme saturation, searches for disconfirming evidence in the data, and questions posed in final interviews with women and physicians. As researchers representing a variety of professional backgrounds, we approached the study with strong interests in women's health, cancer risk perception, and enhancing communication between women and health care providers. One member of our team was directly involved with the hereditary cancer program at the study site.

Findings

Findings of this study are drawn from stories women shared about their experiences in applying for genetic testing for breast cancer risk and are informed by

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Table 2. **Family composition and history of cancer of study participants**

FAMILY AND PERSONAL HISTORY	N	(%)
NUMBER OF PARTICIPANTS WITH FIRST-DEGREE FEMALE RELATIVES*		
Daughter(s)	12	(60)
Sister(s)	9	(45)
NUMBER OF PARTICIPANTS WITH FAMILY MEMBERS DIAGNOSED WITH BREAST CANCER		
One family member diagnosed with breast cancer	12	60
Two family members diagnosed with breast cancer	5	(25)
More than two family members diagnosed with breast cancer	1	(5)
NUMBER OF PARTICIPANTS WITH FAMILY MEMBER(S) DIAGNOSED WITH BREAST CANCER BY TYPE OF RELATIVE†		
Mother	11	(55)
Sister(s)	5	(25)
Grandmother(s)	3	(15)
Aunt(s)	5	(25)
Daughter(s)	–	
PARTICIPANTS DIAGNOSED WITH CANCER		
Breast cancer	2	(10)
Melanoma	1	(5)

* Only two women mentioned their sons during the interview.

† Some participants reported more than one family member diagnosed with breast cancer.

the perspectives of referring physicians. The 20 women interviewed ranged in age from 30 to 66 years; most were married and well educated. Study participants had a range of personal and family cancer histories (Table 2). Eighteen women had at least one family member diagnosed with breast cancer; most were first-degree relatives. Two of the women interviewed had been diagnosed with breast cancer and another reported a diagnosis of melanoma.

The route to genetic testing for breast cancer risk began in many ways. Some informants were motivated by personal experiences with cancer or the need to make health-related decisions that raised concern about their risk for breast cancer (eg, hormone replacement therapy [HRT] or childbearing). Others became aware of genetic testing through physicians, family members, or the media.

Central themes that arose in the analysis included an omnipresent anxiety related to breast cancer risk,

confidence in genetic testing to provide definitive answers, and the experience of “falling through the cracks” as women tried to make sense of their ineligibility. Each of these themes points to potential psychological consequences of ineligibility and women’s need for additional information and support.

“It’s always on your mind”: perceptions of risk.

Underlying women’s experiences of seeking genetic testing was a profound concern about their risk of breast cancer. Women’s perceptions of risk developed over time and were influenced by experiences of family members who were diagnosed with and sometimes died of breast cancer. For some women, one relative’s breast cancer diagnosis was sufficient cause for worry. Reflecting back on the illnesses and deaths of family members as they completed their family history questionnaires was “nerve-wracking” for many.

Women looked to genetic testing to provide them with answers, and most raised the issue with their family physicians. As one woman explained:

I read about [genetic testing] in the newspaper. It seems that people who had a strong history, family history, were potentially eligible, and it appeared that I did have that family history. So that's when I pursued it.

[Interviewer: So, did you talk to your family physician about that?]

Yeah, and that's when he applied for me, as soon as we talked about it.... He didn't know a whole lot about it, except that it was going on and that they would have to make the decision whether I was eligible.

Physicians who tried to reassure women that their risk was not particularly high and that they might not meet the eligibility criteria found some women persisted with their requests. In what could have been an effort to respond to these women's anxiety, physicians accommodated their requests for referral. One physician stated:

Now when the media [come] out with a lot of publicity and some people aren't particularly eligible or the risk isn't as high as they think it is, [they] come in and ask me about it. We just kind of go over it. Like, your risk isn't particularly high. You can see [genetic testing programs] if you want, but your risk isn't as high as you think it is.

A test is a test: hope for a definitive answer. Despite limited knowledge about genetic testing, women had clear expectations about the test and its potential benefits. They assumed that the test was comparatively simple and that there would be a definitive rather than probabilistic result about whether they would get cancer. Few appreciated that, even with negative results, they would have the same risk for breast cancer as women in the general population.

Most women acted on the premise that it is "better to know than not know." They hoped and expected that anxiety associated with the uncertainty of developing breast cancer would diminish and that they would gain peace of mind or at least have "time to prepare for it." Although a few women realized that genetic testing would not provide a categorical answer, they still believed that some relief from their anxiety was possible. Few acknowledged that "knowing" might mean making other complex decisions, such as considering prophylactic mastectomy or chemoprevention.

Many women believed that test results would provide direction for treatment decisions that could "fix" the problem or "prevent" breast cancer from occurring: "If they are telling me I've got this gene, they should also know what I have to do and what would make it go away. I would count on them to do that and give me the right advice. [It would give

me] an opportunity to save my own life or my kids' [lives]."

Women were not only concerned about the consequences of breast cancer for themselves; they were also motivated to protect their families from the burden of cancer. One woman explained, "I'd like to have a chance to catch it early and not go through what my mom is going through and [avoid] putting my family through what everybody else has to go through." Others believed that results would help motivate themselves and their family members (eg, daughters and sisters) to perform regular screening or augment their current screening practices.

Women expected that genetic testing for breast cancer risk could provide more answers than is possible with current technology. Anxieties related to breast cancer seemed to colour women's expectations, even among those who recognized some of the limitations of genetic testing. Genetic testing offered some women the possibility of control in the face of a heightened sense of risk and its associated anxieties.

I think [genetic testing] would offer us at least an illusion of being more in control over the situation. I don't know how much is reality, but I mean [sigh] sometimes I wonder if I ought to even be looking to control these things, whether it's playing God; I don't know.... But I feel I would have a much better handle on things if I knew one way or the other [positive or negative genetic test results].

Physicians in the study were concerned that women did not fully understand the implications of genetic testing for themselves or their families. Although a few physicians introduced some of the more obvious issues (eg, future employability and insurability, HRT, and preventive surgery and medication), others were reluctant to discuss these issues in depth because they believed there was insufficient scientific evidence to guide them. One physician stated, "Most women don't know. They kind of come up with this statement of, 'Okay, I want to know if I carry the gene or not.' They have no idea what the implications are, what it means, what the risks are. I mean, it is sort of like a 'yes or no' test they are looking for."

Falling through the cracks: ineligibility. Women reacted to the letter informing them of their ineligibility with a range of emotional responses from anger, frustration, and fear to disappointment and, for a few, relief. For some, notification of ineligibility confirmed the suspicions they developed when they could complete only a few lines on the family history questionnaire at the time of application. Those who had not even considered the possibility of rejection and who held the greatest expectations for genetic testing

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reacted with the strongest emotions. One woman who responded with anger stated:

I was majorly [sic] pissed off. I thought this was complete discrimination, and who the hell do they think they are to say, "No, you can't have it because there's not enough of one certain kind of cancer in your family." Well, that's crap. One is too many.

Another woman cried when she received her letter. Her expectations of relief for her anxiety were shattered. She stated:

I was just thinking, "Yeah right, you just ran my information through a computer and they did the odds, and the odds were less than what they would consider high risk."... I'm not angry. [I have nothing] against the system.... I was just scared. It didn't help me at all.

Some women perceived the rejection as a barrier to getting further information. Receiving the notification by letter seemed to reinforce these perceptions because of an apparent lack of opportunity to discuss the outcome with anyone from the genetics program. Also, for those women who hoped genetic testing would direct them in making decisions related to HRT or tamoxifen, ineligibility left them still searching for "confirmation one way or the other" of their risk for breast cancer.

With no explanation of their ineligibility, many women tried to make sense of this outcome for themselves:

If genetic testing isn't relevant to my case, then in what sense is it hereditary? Is it that we don't know yet anything about genetics of postmenopausal cancer or is it that, because we don't have siblings, there aren't pieces of evidence in the picture?... I just don't quite understand what the basis for it all is, so yeah, it just leaves me wondering what the big picture is for me.

Accordingly, women sought alternative explanations and drew their own conclusions. Some women thought that others received preferential treatment, attributing eligibility to being "friends" with certain individuals or to being rich. One woman worried that her ineligibility was related to the way she completed the application form. Many women attributed limited access to a lack of sufficient funding for the program.

Women who were upset or disappointed forcefully argued that they should have been given the opportunity for genetic counseling and testing. For some, it was a matter of having a right to the best health care possible. As one woman explained, "If somebody in your family has breast cancer, regardless of age or any other factor, ... I think if they want to pursue it, they should be allowed to."

Many women were willing to pay for genetic testing if this meant it would become available to them. Others thought they should have received testing simply because they believed they were at high risk

or because they might be at the beginning of a family legacy of hereditary breast cancer. These women personalized their rejection, questioning the judgment of genetic specialists and their ability to recognize individuals and families at risk for breast cancer.

I thought I may be someone who may fall through the cracks. ... If it is genetic, then what's to say you won't get it one day and you're the first of your line? So we don't know where it starts; mutation or whatever starts it. It may go underground for a while; we know nothing about it, and it may pop up again three or four generations later.

The letter stating their ineligibility encouraged women to follow up with their physicians, but less than half did so. Women who did contact their physicians reported that they were encouraged to continue close monitoring; most did not discuss the issue any further than this. As a result, many referring physicians were unaware of the emotional consequences of ineligibility and the associated need for further follow up and counseling. Physicians indicated that most women "accepted" the decision and believed that it brought them relief.

One physician thought that it would be worthwhile to obtain more information about the current criteria so that he could explain to women why they were ineligible and reassure them about their risk of breast cancer, if appropriate.

If people don't meet the criteria, they don't have to have the anxiety about having the gene, right? And I think that one of my roles is to be able to reassure people: "Yes, the gene exists and yes, testing exists. But you are excluded by their criteria because you shouldn't have it."

Physicians reported advising a few very anxious women to seek genetic testing from private agencies in the United States or, alternatively, waiting for the criteria in Canada to change and trying again.

Discussion

This is one of the first studies of women's experiences of ineligibility for hereditary breast cancer risk assessment. Although the transferability of study findings is limited by the lack of cultural diversity among study participants and the unique context, the study provides new insights into a dimension of genetic testing that has received little attention. Most important, this study describes women's reactions to ineligibility in the absence of adequate information and support.

Women in this study, although lacking a strong family history of breast cancer, tended to overestimate their risk, resulting in heightened anxiety that was not readily relieved by reassurances from physicians or by being informed of their ineligibility for

genetic counseling and testing. Others also have observed that many women overestimate their risk of developing breast cancer, resulting in perceptions that are difficult to modify.^{12,16-18} The psychological effect of being in a “cancer family” and emotional issues related to breast cancer among high-risk women interfere with accessing needed information and with receiving information on risk.^{19,20}

In this study, women’s search for a definitive answer to reduce their anxiety about their risk of breast cancer provided a strong inducement to pursue genetic testing. Yet, unlike high-risk women, the women in this study had limited access to the information and support they needed. The findings of this study provide justification for hereditary cancer programs to extend services, such as cancer risk assessment and counseling, to low- and moderate-risk women who are concerned about their risk of breast cancer. Some centres already have services for low- and moderate-risk women.

The study also illustrates the need to update physicians on developments in cancer genetics and changing eligibility criteria for genetic counseling and testing. Efforts to increase physicians’ knowledge of genetic testing for risk of breast cancer will help to avoid unnecessary referrals and support physicians in their efforts to explain ineligibility to concerned women.^{1,5,7}

Low- or moderate-risk women who request referrals offer an important cue to health-care providers that underlying issues, such as unresolved emotions related to the death of close relatives from cancer and anxieties related to cancer, need to be explored in more depth. Supportive counseling that goes beyond providing explanations of ineligibility is necessary to address women’s overestimated perceived risk within the broader context of a family that has experienced breast cancer.^{19,21} Emerging evidence suggests that, when discussing genetic testing for risk of breast cancer, practitioners need to be sensitive to differences in goals and priorities between themselves and women who seek this information.²²

Further research is required to determine the best ways to intervene with women who are informed of their ineligibility for genetic testing. Experiences of participants in this study indicate women need information during all phases of the referral process. Some new ways of providing cancer risk information to women at risk of breast cancer are now being tested.^{21,23}

Interventions specifically tailored to women who are interested in genetic testing but not eligible need to include explanations about risk assessment, triage systems for genetic testing and counseling, genetic testing procedures, difficulties in identifying BRCA1

Key points

- This qualitative study examined women’s experiences of being turned down for genetic counseling and testing for breast cancer risk.
- Most women who had been referred for genetic testing and been declared ineligible still believed their risk was high.
- They believed genetic testing could provide more definite answers than is possible with current technology. They hoped to reduce their anxiety.
- Women ineligible for counseling and testing often reacted with strong emotions—anger, frustration, fear, and disappointment—but less than half followed up with their physicians.

Points de repère

- Cette étude qualitative examinait l’expérience de femmes à qui on a refusé du counseling et des épreuves génétiques de dépistage du risque de cancer héréditaire du sein.
- La majorité des femmes qui avaient été aiguillées vers un dépistage génétique et qui ont été déclarées inadmissibles étaient toujours persuadées que leur risque était élevé.
- Elles étaient d’avis que les épreuves génétiques pourraient leur procurer des réponses plus précises, qu’il est possible d’obtenir avec la technologie habituelle. Elles espéraient atténuer leur anxiété.
- Les femmes inadmissibles au counseling et aux épreuves ont souvent réagi avec de vives émotions—colère, frustration et déception—mais moins de la moitié d’entre elles ont fait un suivi auprès de leur médecin.

and BRCA2 mutations, and steps women can take to manage their risk and associated anxiety. Information and support should be provided in more detailed material in their letters of ineligibility, in follow-up telephone calls, or in group educational or counseling sessions. Information aids, such as the one developed by Warner et al,²⁴ could be used to enhance communication between physicians and women when the topic of genetic testing for breast cancer risk arises.

Conclusion

This qualitative study adds new insights to the growing body of knowledge about psychosocial implications of genetic testing for breast cancer risk, especially in relation to ineligibility for testing.

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As the demand for genetic testing for hereditary breast cancer increases, health care providers will be challenged to assist women and their families in making informed decisions related to testing and to provide support throughout the entire referral process. People involved in specialized testing programs and referring physicians must recognize and sensitively respond to women's needs for information and support to reduce the effect of ineligibility and to address women's emotional responses to this experience. ❀

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