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Cultural Aspects of Healthy BRCA Carriers From Two Ethnocultural Groups

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Abstract

We explored the experiences of Ashkenazi Jewish and French Canadian women and meanings attributed to their hereditary breast and ovarian cancer (HBOC) risk. We purposively sampled 40 BRCA1 or BRCA2 (BRCA) mutation carriers and conducted theoretically driven semistructured interviews. According to content analysis, participants from these two ethnocultural groups held divergent meanings associated with being a BRCA carrier and different views pertaining to the illness experience and risk awareness. All participants identified a genetic basis; however, the French Canadian women also expressed other causes. The French Canadian women reported not knowing other carriers in their social environment, whereas the Ashkenazi Jewish women emphasized a strong sense of community contributing to their ethnic risk awareness. Based on these findings, we suggest that French Canadian women could benefit from greater awareness of the HBOC genetic risk and that health care providers should consider ethnically related and individual-based experiences and meanings during counseling.

Keywords

cancer, breast; cancer, genetics; content analysis; culture / cultural competence; psychosocial issues; risk

Approximately one in nine women in North America is expected to develop breast cancer in her lifetime (American Cancer Society, 2013; Canadian Cancer Society, 2013). Although less than 5% of breast cancers are attributable to hereditary cancer syndromes, women with hereditary breast and ovarian cancer (HBOC) because of a mutation in BRCA1 or BRCA2 (BRCA) have a 45% to 88% lifetime risk of developing primary breast cancer and 11% to 65% risk of developing ovarian cancer (Antoniou et al., 2003; Evans et al., 2008). In addition, Metcalfe et al. (2004) found that women who are BRCA mutation carriers have a significantly higher risk of developing a second breast cancer than women with a nonhereditary form of the disease.

BRCA mutation carriers can undergo regular breast imaging, chemoprevention, and risk-reduction surgery to manage their breast cancer risk. Increased surveillance includes regular magnetic resonance imaging of the breast (Leach et al., 2005). Chemoprevention using hormone-based treatments such as tamoxifen can be effective in decreasing the risk (Domchek et al., 2010). Surgical interventions with proven efficacy in reducing the risk include bilateral prophylactic mastectomy (BPM), which can reduce breast cancer incidence by more than 95% (Geiger et al., 2005; Hartmann et al., 2001; Rebbeck et al., 2004), and bilateral prophylactic salpingo-oophorectomy (BPSO), which can have a protective effect in BRCA mutation carriers, particularly if performed before the age of 50 years (Domchek et al.).

Cultural factors shape health-related beliefs, behaviors, and values. Cultural responsiveness is fundamental in exploring the various agendas in interview dynamics. Genetic counselors impart their professional wisdom to counselees, whereas counselees have to consider whether they need to revise their understanding of genetics and integrate this expert knowledge and its implications into their own life (Armstrong, Michie, & Marteau, 1998). Cultural differences can be implicated in disparities in health care, and researchers can gain insight into cultural responsiveness, appropriateness, and effectiveness of

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clinical services for people from diverse ethnocultural communities through studies of cultural influences (Kirmayer, 2012).

In countries with historically diverse immigrant populations, such as the United States, Canada, and Australia, inquiring about ethnicity is considered an essential part of providing appropriate care in medical settings, particularly in the field of medical genetics. According to Belkić et al. (2010), disclosure of ethnicity has been more controversial since the Second World War, and many European nations tend to avoid identifying individuals on the basis of ethnicity; consequently, studies regarding ethnicity and psychosocial aspects of genetic testing for breast and ovarian cancer have been conducted mainly in the United States, Israel, and Australia.

In the United States, African Americans (Kinney et al., 2006) and Latinos (Lagos et al., 2008) have been the most investigated groups when considering the sociocultural factors related to cancer genetic counseling and testing. In ethnographies of Chinese Australians (Eisenbruch et al., 2004) and Arabic Australians (Saleh, Barlow-Stewart, Meiser, Kirk, & Tucker, 2011) conducted in Australia, the focus has been on patient experiences related to cancer genetic counseling. In studies of transcultural genetic counseling practices conducted in the United Kingdom, the roles of both the counselee and counselor have been evaluated (Middleton, Robson, Burnell, &Ahmed, 2007). To the best of our knowledge, no study has yet been conducted to evaluate the sociocultural aspects of cancer risk experience according to different ethnocultural groups in Canada.

In general, little is known about the cultural and system-related factors associated with genetic testing (Meiser et al., 2006-2007); however, according to some surveys, cultural factors might affect HBOC-related health behaviors. In a study of 2,677 women with BRCA mutations from nine countries, the use of different preventive options varied substantially according to the country of origin. Although many opted for prophylactic oophorectomy, only a minority of women with BRCA mutation opted for prophylactic mastectomy or used tamoxifen for preventing hereditary breast cancer (Metcalfe et al., 2008).

In another multinational survey conducted in Montreal (Quebec, Canada), Marseilles (France), and Manchester (United Kingdom), the acceptance of preventive strategies (Julian-Reynier et al., 2001) as well as clinical practices related to hereditary breast cancer (Bouchard et al., 2004) were investigated. According to the findings, cultural factors might partially explain behaviors in these domains. Julian-Reynier et al. noted that "operationalizing culture in quantitative surveys" (p. 966) can be challenging, and that qualitative research is required to fill the gaps.

In Montreal, the majority of women undergoing cancer genetic counseling belong to either of the two founder populations: French Canadian or Ashkenazi Jewish. In Quebec, 6,000,000 French Canadians are descended from 8,500 French settlers who arrived in Nouvelle-France between 1608 and 1759. Moreover, founder mutations have been identified in 8% of women with ovarian cancer (Tonin et al., 1998) and in 5% of women with breast cancer under the age of 50 years (Ghadirian et al., 2009). At least 15 BRCA pathogenic mutations have been reported, four of which were identified in 82% of the mutation-positive families (Simard et al., 2007). The overall prevalence of BRCA founder mutations in French Canadians, i.e., approximately 0.25%, or 1 in 400, is comparable to that in other populations (Ghadirian et al.).

Genomic analysis has been used to address the origin of the Ashkenazi Jews. According to the Rhineland hypothesis (Atzmon et al., 2010), Ashkenazi descended from a relatively small group of 50,000 German Jews in the 15th Century, whose population rapidly expanded to 5,000,000 at the beginning of the 19th Century. According to the Khazarian hypothesis (Elhaik, 2013), the European Jewish population has a mixture of people of Khazarian, European, and Middle Eastern origin as a result of more than 400 years of integration and migration in the Caucasus. According to available evidence, a large number of Ashkenazi Jewish families with breast and/or ovarian cancer can be linked to inherited BRCA mutations. Approximately one in three Ashkenazi Jewish women affected with ovarian cancer (Tobias et al., 2000) and 1 in 8 women affected with breast cancer (Warner et al., 1999) carry one of the three founder BRCA mutations. The prevalence of these three founder mutations in the general Ashkenazi Jewish population is estimated to be 1 in 40 (Struewing et al., 1997).

Psychosocial aspects of genetic testing among Ashkenazi Jewish individuals have been considered in previous reports (Andrews, Meiser, Apicella, & Tucker, 2004; Apicella et al., 2006; Metcalfe et al., 2010; Phillips et al., 2000; Press, Yasui, Reynolds, Durfy, & Burke, 2001). The experiences of Quebec BRCA carriers or untested women at risk of carrying a mutation have been reported in only one article (Proulx et al., 2009). This latter study was conducted in an experimental breast cancer screening program and, given the population in Quebec, it is reasonable to assume that many of the participants were French Canadians. To our knowledge, no cross-cultural study has yet been conducted comparing Ashkenazi Jews and French Canadians for cancer-specific genetic risk. Therefore, we explored the experiences of Ashkenazi Jewish and French Canadian women and meanings attributed to their HBOC risk.

Theoretical Background

We reviewed the literature in the anthropology and sociology fields to identify methods for assessing multidimensional illness representations. We identified three interview formats published in the French- and English-language literature: the Explanatory Model of Illness Catalogue (Weiss, 1997; Weiss et al., 1992), the Short Explanatory Model Interview (Lloyd et al., 1998), and the McGill Illness Narrative Interview (Groleau, Young, & Kirmayer, 2006). Each format is based on the Explanatory Model of Illness. Kleinman (1978) defined this model as a notion about an episode of sickness and its treatment employed by all those engaged in the clinical process, "contain[ing] any or all of five issues: etiology; onset of symptoms; pathophysiology; course of sickness (severity and type of sick role); and treatment" (1978, p. 87–88).

The McGill Illness Narrative Interview (MINI; Groleau et al., 2006) is comprehensive and includes the contribution of Young (1981, 1982) on illness experience. Young argued that "the relation between what a person says and what he thinks, knows, and feels is usually problematic, but most medical anthropologists ignore this problematic nature by assuming that informants can be treated as if they were rational men" (1981, p. 317). Accordingly, instead of logical and coherent schemas organized around causal attributions, individuals employ "multiple representational schemas and modes of reasoning to produce illness narratives that are complex and sometimes internally inconsistent or contradictory" (Groleau et al., 2006, p. 675).

In addition to explanatory models, Young (1981) considered two other forms of knowledge that shape an individual's illness comprehension: prototypes and chain complexes. He explained that a prototype is used for analogical reasoning to interpret future instances. When a person uses prototypes, he moves "from particular (prototype) to particular (experiential referent), rather than from particular to general (inductively) or from general to particular (deductively)" (1981, p. 330). In contrast to explanatory models, large numbers of people do not share prototypes, and prototypes are not strongly causal; however, they can be powerful tools in shaping beliefs. Chain complexes are "products of experience" (Young, 1982, p. 273) or the sequence of events surrounding the symptoms. Chain complexes represent implicit learning and procedural knowledge structured in terms of links or associations largely outside the awareness of an individual. Experiences can be linked metonymically or by contiguity to the health problem (Groleau et al., 2006).

Finally, considering the contemporary culture theory, Groleau et al. (2006) stated, "The MINI does not sharply distinguish between personal and cultural meanings, which are intertwined in any individual's account" (p. 677). We can use an example to illustrate illness representations based on the explanatory model and familiar prototypes in a narrative context: A BRCA carrier states that her cancer risk results from a genetic mutation transmitted from the maternal side (explanatory model of her BRCA status). She then mentions that she does not have to be worried about breast cancer because the women in her family only develop ovarian cancer (her prototype). She adds that if a relative develops breast cancer, she would consider herself at risk and would undertake preventive action to lower her breast cancer risk. The explanatory model is consistent with the medical knowledge acquired; however, the revealed prototype is salient in determining the health behavior. By considering these conceptual themes, we can identify inconsistencies and complexities in narratives and relate them to meanings and health behavior.

Methods

Participants and Setting

For this study, genetic counselors contacted 49 Canadian women who were consulting them, of which 40 agreed to participate in the study: 20 Ashkenazi Jewish women and 20 French Canadian women. No explanation was provided for the nine women who refused. The participants were referred to the medical genetics service of university-affiliated hospitals serving both French- and English-speaking patients in Montreal. They were purposively selected according to the following criteria: (a) women who self-reported being of French Canadian or Ashkenazi Jewish descent, (b) unaffected by breast cancer at the time of genetic testing, (c) carrier status known for at least 3 years, and (d) the decision in favor of or against BPM made prior to breast cancer diagnosis, if applicable. Women from each cultural background were matched according to their health-behavior decisions related to the management of breast cancer risk. The first author, a Brazilian psychiatrist fluent in both English and French, conducted all interviews; eight interviews were conducted in French and 32 in English. The research ethics review board of the university-affiliated health center approved the research protocol and consent forms.

Procedures

The narratives of the women were elicited using the MINI to explore meanings, experiences, and behaviors related to illness (Groleau et al., 2006). This theoretically driven, semistructured interview consisted of questions allowing the participants to explore three distinct forms of reasoning and representations when describing illness

experiences. The interview was unstructured at the outset to encourage the development of illness narratives. Illness experiences and life events are linked without explicitly attributing causal relationships in "chain complexes." These intuitive connections constitute metonymical reasoning. To conceptualize living with a BRCA mutation, interviews began with an open question about the experiences of the participants with regard to their genetic status. In the second and third parts of the interview, causal and analogical reasoning related to the genetic condition of the participants was examined. At this stage of the interview, explanatory models (cause-and-effect relationships) and prototypes (events that lend meanings to a present illness) were expected to emerge from the narratives. In the last part of the interviews, pathways to healing and the global impact of the genetic condition on the lives of the participants were explored.

Interviews were conducted between June 2009 and February 2010 at a participant-chosen location (homes, workplaces, or the university-affiliated hospitals where genetic testing was performed) and lasted for an average of 77 minutes (two interviews lasted less than 1 hour). All the interviews, except that of a woman who lived more than 500 km from Montreal and preferred to be interviewed by an Internet-based video conference using Skype, were conducted face to face.

Analysis

All interviews were audio recorded, transcribed verbatim, and transferred to qualitative data analysis software (ATLAS.ti, 2009) for coding. We performed content analysis (Patton, 2002) using thematic and conceptual codes. Thematic codes were first extracted using a data-driven inductive approach. A deductive approach was then used for the conceptual codes. The MINI questions predetermined these codes according to three knowledge structures: explanatory models, prototypes, and chain complexes (Groleau, Whitley, Lespérance, & Kirmayer, 2010). Using this analytic procedure, we aimed to identify common explanatory models, prototypes, and event types potentially linked to the genetic status. Once detailed descriptions and metaphors were extracted, we performed cross-interview analyses to report emergent themes. In the final analysis we compared the convergent and divergent themes of collective meanings from narratives according to the ethnocultural group.

To provide a general description of the background of the participants, demographic data were separately tabulated according to the ethnocultural group (see Table 1). Statistical tests for categorical variables were determined using Pearson's chi-square test or Fisher's exact test if any table cell count was less than or equal to five. One-way analysis of variance was used to evaluate whether the outcome and number of years of awareness of the carrier status were associated with the demographic variables. Analysis was performed using the statistical software Stata (StataCorp, 2003).

Table 1. Participant Characteristics.

Demographic Characteristics	Ashkenazi Jews $N = 20$	French Canadians $N = 20$
Age		
Mean age (years)	46.3	43.6
Range (years)	30–67	29–58
Knowledge of carrier status		
Mean time (years)	6.9	5.1
Range (years)[a]	(3–12)	(3–11)[a]
Marital status		
Single	1	2
Married/common law	15	16
Divorced/widowed	4	2
Offspring		
Women with children	17	18
Daughter(s)	30	16
Son(s)	15	21
Educational background		
Secondary[b]	3	15
Postsecondary[c]	17	5
Family income		
Less than $20,000	—	1
$20,000–$39,999	3	3
$40,000–$59,999	—	1
$60,000–$99,999	4	7
more than $100,000	13	8

[a] $p = .046$ (One-way ANOVA).
[b] $p < .001$ (Fisher's test) Secondary education—high school or general and vocational college.
[c] $p < .001$ (Fisher's test) Postsecondary education—bachelor's or master's degree.

Results

Participants

The Ashkenazi Jewish and French Canadian groups were similar with respect to all major variables: age, marital status, number of breast- or ovarian-cancer-affected first-degree relatives, having had children, proportion of adult children who knew of their genetic status, number undergoing BPSO, and number undergoing breast reconstruction after BPM (see Table 2). Univariate analysis revealed that the Ashkenazi Jews knew their mutation status longer than the French Canadians ($p = .046$); however, this was not significantly associated with the choice of risk management, family income, education level, or marital status. Differences in the education level by ethnicity were also

Table 2. Hereditary Breast and Ovarian Cancer Family History.

Family History	Ashkenazi Jews *N* = 20	French Canadians *N* = 20
Mean number and range of affected relatives[a]	2.4 (1–6)	3.3 (1–15)
Women with affected FDR[b]-breast cancer		
None	10	7
1 FDR	6	11
2 FDR or more	4	2
Women with affected FDR-ovarian cancer		
None	16	14
1 FDR	4	6
Mean number and range of BRCA carriers relatives	25 (0–8)	3.3 (0–10)
Women with children aged ≥18 years	6	8
Children aged ≥18 years	18	15
Untested	14	12
BRCA noncarrier	1	3
BRCA carrier	2	—
BRCA carrier + breast cancer	1	—

[a]Breast and/or ovarian cancer.
[b]First-degree relative (mother, sister, or daughter).

statistically significant ($p < .001$). Ten French Canadian women chose BPM and another 10 opted for intensive screening. In the Ashkenazi Jewish group, 7 women underwent BPM whereas 13 chose screening. All participants had access to all publicly funded risk-management options provided by the Quebec health care system.

BRCA Carrier Narratives

Narratives often started with a description of family history, focusing on breast- or ovarian-cancer-affected relatives and how their diagnosis led to a referral to undergo BRCA genetic testing. The first decision made was the time to be tested. Some women considered themselves to be at high risk for breast cancer before knowing their genetic status, whereas others became aware only after discovering their genetic status. Differences were observed between the Ashkenazi Jews and French Canadians with regard to how decisions were made and the consequences of these decisions as a healthy carrier. In the following sections, we present the convergent and divergent themes that emerged from the narratives of the women. When reviewing the divergences, clear differences were observed between the two groups in terms of socialization of their BRCA carrier experience.

Emergent Themes

Going through the BRCA risk assessment. Prior to genetic testing, cancer risk experience was linked to witnessing or listening to the narratives of women with breast or ovarian cancer. Both the Ashkenazi Jewish and French Canadian women characterized genetic testing as a new dimension in their cancer risk experience. The results of genetic testing led to the creation of new awareness:

> Knowing the gene was more serious, it was like it wasn't a diagnosis of cancer, but it was like getting more chances for me that it would happen. (French Canadian [FC], mastectomy [M])

> My mother died of cancer, and my aunt had cancer at twenty-nine. But I think you have the feeling that it's always for others. You think about it, but you don't have that in mind all the time. But I think after you undergo the test and it's positive, you have it in your mind all the time. That's the difference between the before and the after. (FC, screening [S])

Women underwent genetic testing after a relative—usually their mother or sister—was tested. They were often surprised when the index case came from the paternal side. In addition, a recent cancer-related loss often triggered the desire to be tested:

> When I went for testing, I was convinced before I even got the results that I was a carrier just because of my family history [her only sister diagnosed with breast cancer 5 years earlier, and their mother had been recently diagnosed with ovarian cancer]. But I have to tell you that when they tell you that you're a carrier, it's like somebody just hits you over the head with a baseball bat. When they tell you that you're a carrier or you have cancer [she had thyroid cancer], it's like, my God, whether you thought you did or not, it's like, "Oh my God!" That word is enough to make you keel over. It's awful. It really is. It's almost like a death sentence. (Ashkenazi Jewish [AJ], S)

> I was surprised because, although I was involved in the charity [for breast cancer], I never thought, with my aunt [paternal side] dying of ovarian cancer, that I should get checked. It never occurred to me. But my aunt who died, her daughter has the gene and her husband is a doctor. He suggested everybody in the family to go get tested. (AJ, S)

Although experiencing a loss can be pivotal to raising the question of being tested, the decision to undergo genetic testing remains a personal choice. Some women took many years before deciding to undergo the test. According to some women who chose BPM, preparatory work is required. For instance, they considered that the right time to undergo testing was when they were ready for preventive surgery:

> [For] at least ten years, I have had phone calls to go get tested, the blood test. I was saying no, no, no, I wasn't interested. Then, at thirty-eight years of age, I received another phone call to go get the blood test and I agreed. Because I had my daughter, I didn't wanna know then. I wasn't interested because my mother was sick and I was taking care of my mother, then me, no, I didn't want [the blood test]. (FC, M)

> When my mother suggested that I should undergo testing, I resisted it a little bit at the beginning because I felt it was important to sort of have a plan of action in place before. Because to have the knowledge and to not be able to do anything about it was, I think, scary. So, I talked to a lot of people and thought about all the different options before I actually went for testing. So, by the time I went for testing, I already had certain decisions made in my mind. (AJ, S)

Some women reported uncertainty about the impact of knowing their genetic status. Many women recalled—while crying—how it had unearthed past distress and loss, particularly in the BPM group:

> You have to grieve, it's a grief. It's a grief of what comes with surgeries, of what you were expecting [genetic testing]. The grieving was more about finding out that yes, it is that yes, I'm, I have that, so I have to deal with that. Before, it was a risk, it was a family history. Now, it's like okay. Now, it's not just a family history, it's me who's at risk. (FC, M)

The women relied on many metaphors to describe the dimensions of suffering related to carrying a BRCA mutation, including "the insidious killer," "the sleeping evil," and "Pandora's box." According to one woman, knowing one's carrier status was not a welcome "gift" because of a painful dimension:

> I think other people look at it like it's a gift to have this knowledge, and they'll use the knowledge and undergo preventive surgeries. Whatever. I don't look at it as a gift of knowledge. It's not, I don't know, it's not how I interpret it. (AJ, S)

Coping with "the biggest worry." The participants told their children about their genetic status, and many referred to the painful uncertainty or the certainty of having transmitted the BRCA mutation to their children. Many talked about the fact that their children could be tested earlier than they had been. Although most women emphasized that it should be their children's choice, they also acknowledged the implications of knowing the genetic status (e.g., for family planning):

> She was like twenty, twenty-one, and we were talking about it in the car. Then, I turned around and she was crying. Her life is starting. When I found out this, I was a bit older; I was a lot older than her. So, my only advice to her is just take it out of your head and live your life as best [you can]. Do what you wanna do. Travel, get married, have kids, and do everything that you wanna do. Later, when all that is finished, then you can decide if you wanna undergo testing or not. But not before, 'cause I think it will rob you of your life. You need to live. If you're one of the really, really unlucky people who develop breast cancer when you're twenty-five, well then we'll deal, we'll deal with it. That was my advice to her. (FC, M)

> The question for me was at a certain point, when they start having partners, then there's an ethical question for them. There's the implication for them in terms of their own health and their own strategy about dealing with it. It's still early for them. But if they're going to have partners, there's a certain moral obligation, I think. There's an ethical question that they need to, I think, in terms of planning families. (AJ, S)

The orthodox Jewish women were less likely to talk with their peers because they were afraid of stigma that could prejudice their daughters' potential for marriage. Although this was not as prevalent among the French Canadians, stigma remained a concern with their potential spouses:

> I spoke about that with two of my very close friends. Because I think there is, at least in the Jewish community, there is a little of . . . let's say if I will marry. Let's say for marriage purposes, maybe someone would say, "Oh I, I don't know if I want to marry your daughter because maybe she is a carrier." So, in a way, I don't talk. There are just two of my best friends who know everything, but otherwise, I don't tell people. When I had to undergo surgery, I told them I was undergoing hysterectomy. (AJ, M)

> I wonder if he had known that I had the gene, would he still have married me because of what he says, because it's a . . . I don't know, I don't know, but I . . . sometimes he says, "No, no." It's a big thing even for their spouses to know. So, if my daughter has the gene maybe her future husband [is] not gonna want to marry her. Not everybody can handle that properly, or the way you want them to handle it. Sometimes, it's just too much for people to handle. (FC, M)

Making sense of being a BRCA carrier. Several positive and negative meanings unfolded during the narratives related to knowing the carrier status. We observed that sociocultural dimensions played an important role in the divergent meanings for the French Canadian and Ashkenazi Jewish women (see Table 3). The French Canadian women viewed testing and the accessibility to health care resources following a test as an outstanding opportunity. This was an important determinant of how some women labeled their condition. For instance, some labels included: "insurance policy"; "assurance"; "relief, because for me

Table 3. Divergences on Emergent Themes and Illustrative Statements.

Emergent Themes	Ashkenazi Jews	French Canadians
Sociocultural meaning of being a BRCA carrier	Because I am a BRCA carrier, I have been in a very high-risk program with very careful monitoring. So, I will say being a carrier means that it saved me because I would not have been in this program and I would not have been so diligently followed up. (recently diagnosed with breast cancer)	I think I am lucky. I feel more safe. I see people who have a requisition for mammography; they wait months and months, and they wait months and months to see a specialist. Being a carrier opens up a lot of doors.
Shared experience	You don't know how many people got tested when my daughter got sick. You should see, that's something that you should really take note of. The impact of knowing somebody personally, the affect that it has. So, she set off a huge chain reaction.	We don't talk about disease. We believe that perhaps by not talking about it, we won't attract it. . . . So, if the disease is not around, we won't get sick. By thinking about it, our minds suffer, our bodies will end up suffering too. So if we try to remove the suffering from our minds, maybe our bodies won't know suffering. So far, it's been working for fifty-five years.
Ethnic risk	It's genetic concentration, you know, the fact that you have Jews marrying Jews marrying Jews, and so on and so forth.	I don't know. I don't know a lot. Is it something that is related to my origin? To the, my Quebecoise, uh, origin? I don't know. I know I've heard a lot of person, like that had breast cancer. But I never heard about genetic mutation, except in my family. I never heard anybody talk about that.

knowing that I am followed very closely by very professional people, it takes a lot of weight off my shoulders"; a "gift, because if not, I had not been at the [university-affiliated hospital]." At times, this last expression was used as a metaphor when trying to make sense of being a BRCA carrier:

> I find I'm a lucky one because I know a lot of women at my age, they don't have the chance that I got to be followed so closely for my breast. The only difference between me and other one is I know that I can get it. The other one doesn't know but maybe she had more chances than me to have it. Myself, by knowing it well, I go regularly. For me it's [an] insurance policy. (FC, S)

The French Canadian women who opted for breast cancer screening often expressed gratitude for the health care system, whereas those who underwent BPM viewed it as a "mixed blessing." They also compared themselves with other women without the same opportunity of close monitoring. Moreover, carrier status meant that access to other medical services was easier. As a French Canadian participant illustrated, being a carrier "opens up a lot of doors," making her "well surrounded" and medically well supported. Among the Ashkenazi Jewish participants, receiving specialized care was not spontaneously recognized in their narratives. One woman who subsequently developed breast cancer felt well cared for because of the close monitoring.

The two cultural groups converged in considering it a privilege to know their genetic status and being able "to do something" with this knowledge. This idea of privilege of knowing was emphasized in the BPM group, whose participants felt they were able reduce the risk of developing cancer:

> So, I considered myself very, very lucky. Very lucky because I would have ended up down the same path as my mother. I looked at it, to find out that I had the gene, as an opportunity because I could do something about it. I felt very grateful that I never had cancer. My cousin found out and went through all surgeries I went through, [but she] had cancer twice, chemotherapy twice, and radiotherapy twice. I felt lucky that I was, you know, deprived of that. I felt very, very lucky that research had progressed to this point, that I was being offered an option. I know my mother would not have hesitated to take any measure to be around. So, I never thought twice. It was the best thing I've ever [done]. It's been ten years now." (FC, M)

> So, I think I'm a lucky one, in a way, that I was tested. I mean, someone else had cancer, but I was the lucky one as I was able to do something to try to avoid having cancer and chemo[therapy], and all the consequences of that. (AJ, M)

Conceptual Themes

Prototypes of being a BRCA carrier. In the last decades, the public has become conscious about illness experiences, particularly in Western cultures. More people are willing to narrate their stories to the media about difficult times, difficult decisions, recovery, and survival. In Quebec, Ashkenazi Jews and French Canadians are exposed to different patient testimonials. Strikingly, the French Canadian participants were not aware of BRCA carrier

Table 4. Divergences on Conceptual Themes and Illustrative Statements.

Conceptual Themes	Ashkenazi Jews	French Canadians
Prototypes of being a BRCA carrier	You saw the Oprah show? About, with Christina Applegate? No?! I did it because my daughter was in the audience. She's an actress. Beautiful actress. She had the exact same cancer as my daughter. It's the exact same surgery and she was very open about it. She did it for other women and it was amazing. I'm impressed with people like Christina Applegate, with these people how strong they are dealing with it. I'm impressed with my daughter. I mean she's unbelievable.	I would say in all my environment aside from when you go to [the hereditary cancer program] that people know. Nobody knows aside from my family doctor. I've never heard of BRCA1 really in the media.
Explanatory model of being a BRCA carrier	I have no idea, and I've given it zero thought, to tell you the truth. Because it's there. It's just part of my genetic makeup.	I have no idea where it comes from, because if it's genetic, where does it start? From whom? We don't know. Was it brought over from Europe? When it's passed from one generation to the other, maybe it existed forever or maybe only since modern times. It's hard to tell, is it in the food that caused it, you know made it happen? We have no idea where it comes from, we didn't know what happened before.

testimonials in the media, although one woman mentioned Genevieve Borne, a television personality who had breast cancer, necessitating mastectomies in her 30s. In contrast, the Ashkenazi Jewish women not only heard of different people with the same experience but also pointed out a specific young actress with the BRCA mutation who developed breast cancer and underwent BPM (see Table 4). This testimony was shown on a famous talk show and had a profound impression on some of the participants:

> Christina Applegate, she's probably a carrier. Because she underwent, you know, radical surgery, when I don't think it was, had spread to both breasts when diagnosed. I think she's definitely raised a lot of awareness about, you know, mastectomies and preventive surgery. Whether she's a carrier or not, she's definitely attempted to raise awareness of that. (AJ, S)

These differences in narratives between the Ashkenazi Jewish and French Canadian women with regard to public prototypes are important in the social construction of risk awareness related to BRCA gene status, breast cancer, and related health behaviors. Women are known for their activism in the breast cancer movement worldwide. The Ashkenazi Jewish participants made special reference to a local HBOC Foundation, specifically dedicated to support breast- and ovarian-cancer-afflicted families. Some of the Ashkenazi Jewish women were proud to have volunteered for the HBOC Foundation-mandated fundraising and other activities, which gave them a sense of belonging. In contrast, only a few of the French Canadian participants referred to a conference for which they received an invitation from their genetic counselors, and they did not identify it as being an HBOC Foundation-sponsored event. There was only one French Canadian woman who spoke about her participation in *Ringette Skates for a Cure*, which raises funds to benefit the Quebec Breast Cancer Foundation.

Distinctly different from the Ashkenazi Jewish women, the majority of the French Canadian women were unaware of other BRCA carriers in their social environment:

> I don't know anybody that they know genetically carry cancer. I don't know any family that I can say that it's genetic. I work in health care and went through a lot of families, but I never heard that, let's say that they would say it's genetic or something. No. (FC, S)

When asked about their knowledge of the experience of other BRCA carriers in their social network of friends, work, and so forth, one French Canadian woman spontaneously said,

> But I would have liked to. I'm sure that at the [university-affiliated hospital] they must have people like me. We could communicate with these people and talk about, you know, how they handle [it], how they live like that, and how I live like that. I would have liked that. (FC, S)

Genetic specialists regularly promote the exchange of experiences between carriers, particularly when contemplating risk-reducing options. In this study, the French Canadian women expressed a desire for these interactions: "They've [department of medical genetics] given

my name to other patients so that they can ask me about my experience. But in my social circle, no" (FC, M). In contrast, we identified from the Ashkenazi Jewish narratives that this ethnic group had good social networks because "it's a small community," where they "just all know each other." From their social relationships, the Ashkenazi Jewish participants were familiar with the issues surrounding genetic testing, even without necessarily having lived with an affected relative. With regard to experiential knowledge, they could describe different reactions: "I never lived through cancer with anybody. So, psychologically and emotionally, I understand why other people, you know, can have issues around knowing or not knowing, and testing or not testing" (AJ, S).

With fewer social prototypes available, we looked for familial prototypes in the French Canadian narratives. Even within this social interaction, the French Canadian women lived the BRCA experience privately and did not share their fears, thoughts, or illness experiences:

> But I said I don't know if all my aunts [BRCA carriers], and if they think the same way because we never discuss about it. We're always together. But we're more together to have fun. Nobody likes to talk about health problems, you know. (FC, S)

Perhaps by not talking about the disease, or other problems associated with suffering found in the French Canadians' narratives, this can be related to the ideal of being positive, of "joie de vivre" (the joy of living). Almost all of the French Canadian participants emphasized this emblematic value. One woman told us, "Our family looks at the bright side. We are all positive. We try to see the best of things" (FC, M). In contrast, we found that the Ashkenazi Jewish women capitalized on the social opportunities to communicate their illness experience:

> We have the opportunity in school [her work] to talk about all these different types of cancers that one can experience, and obviously what people think and stuff like that. So, in my milieu, there are a lot of people. (AJ, S)

Explanatory models for being a BRCA carrier. All participants attributed their carrier status to genetics and often described it in a few, mainly biological terms, such as the BRCA gene, mutation, and inheritance. They also emphasized that their BRCA mutation was neither something they could change nor something related to personal action. Many stated that they did not know why it existed:

> Genetic. I don't think there's an explanation related to that. I don't know what have caused it. Where it's coming from, when did it start. I don't know if anyone knows. It's in my genes. It's my . . . it's in me. I don't think there's a reason why me or why not, or why some person has something and some other don't. It's not because I smoke. It's not related to, because I'm not doing sport or . . . . It's just there. There's nothing I can fight. It's in my body, so it's not under my control. (FC, S)

> Why my family inherited this gene, I don't know. So, dating back to when the first person in my family started, you know, first had it, I probably couldn't answer that. I wouldn't have any other explanation as to why my family has it. No. We don't have anyone that I know had the gene in my family, namely my father and my paternal grandmother, neither of them were smokers. As far as I know, they were relatively healthy. Same for myself: I've never been a smoker, I eat very well, and I stay in very good shape. So, there's no explanation why I would have inherited it and not my sister or my brother. That's a mystery to me. (AJ, M)

Cancer emerged at the forefront, however, when participants were asked to explain their genetic condition and the factors often associated with cancer development: the problem was not having the gene, but having cancer. For instance, one woman labeled her health condition as "I genetically carry cancer," and said, "Too much artificial things in food that we eat, and pesticide. I always say, I'm sure, cancer has to do something with that" (FC, S). In other instances, overall health vulnerability to environmental factors was revealed when the participants talked about secondary causes:

> Everybody is born with some kind of potential to have cancer, but it turns when there's a lot of things—either exposure to certain things in our environment or stress factors—just make the body react in a certain way. (AJ, S)

> What caused it? I really think it's the genes my mother transmitted to me. The secondary causes would be big traumas and weaknesses in your life, where I guess the cancer can get a hold of the better side of you. It could be a factor, but I don't think it's the only factor. (FC, S)

We found an important distinction between the two cultural groups when women addressed the meaning attributed to their genetic status. The French Canadian women provided diverse significance, whereas the Ashkenazi Jewish women almost exclusively referred to medical knowledge. One Ashkenazi Jewish woman even criticized the question of looking for a hypothetical explanatory model because, for her, medical knowledge was the only acceptable belief system:

> Interviewer (I): According to you, what caused it?
> Participant (P): What caused? My family history.
> I: Do you think there are any other causes that you think played a role?
> P: For me to get the gene? No.

I: Secondary causes?
P: Well, it's genetic, I mean, isn't that the definition of genetic?
I: It's part of my questions.
P: Okay. Do people ever say yes, they think there is a secondary cause?
I: Sometimes.
P: Really?
I: Yes.
P: But isn't, I mean, there is a right or wrong answer?
I: This is not the point here.
P: I mean, it's genetics; it's a genetic test. Why they think there's a secondary cause, how they got the gene? You're born with a gene, aren't you?
I: Yes, we are not discussing this.
P: Am I wrong? You're born with the gene, right?
I: Of course, you are not wrong. (AJ, M)

Another Ashkenazi Jewish woman searched for an explanation but then explained how her actions lowered her risks of developing breast cancer, which were limited to the well-established factors associated with the disease:

I: According to you, what's the main cause, the primary cause for that, this whole problem?
P: The mutation, that I have a mutation.
I: Do you think there is a secondary cause that plays a role?
P: For the mutation?
I: Or for the disease to occur?
P: To have breast cancer, you mean, or to have the disease?
I: Yes.
P: [pause] I don't you, I mean [pause], I did everything that was possible for me. I mean like, I have babies, I breastfeed them, and I have tamoxifen. I mean, besides that there is a point that you can do nothing more. I mean, if you are, if you have the mutation, that's it. There is nothing else to do. I did what was possible. (AJ, M)

Although through the narratives of the French Canadian women the gene was identified as the cause, many attempted to signify their experience of being carriers. One French Canadian woman described the following when she received her positive test result: "I cried and I asked why. They don't know, but they do studies now regarding the gene that is passed on from generation to generation" (FC, M). The French Canadian participants were willing to question it further. For example, they compared themselves with other families to seek answers: "If I compare my family with any other family, I don't see anything specific that I could say it could be different" (FC, S). Some of the French Canadian participants attempted to find a reason for the BRCA mutation in their family, and one woman reported an association between the defective gene, birth defects, and sexual history:

> I inherited a defective gene. I guess for me I see it as a defect. My mother had performed some research into her family history, and she believed it was because one of her ascendants had contracted a sexually transmitted disease. She believed that [is] where it started. But whether that's true or not I have no idea. I don't know that can happen that, you know, a gene becomes defective because of that. Some people are born with things that you can't necessarily see. Some people have like, for example, I have a little cousin that had Down syndrome. It's the same thing. It's a birth defect. (FC, M)

The French Canadian women attempted to explain why some relatives carried the familial BRCA mutation whereas others in the family did not. Family resemblance and lifestyle were used as examples to help them understand differing genetic statuses among relatives:

> Among the three of us, two have the gene. What's interesting about it is that my younger brother and me both look like my mother and that we both have the gene. The one who looks like my father doesn't have the gene. (FC, M)

> I was very disappointed when they gave us the letter [genetic result]. For myself, the two that I thought would be positive because they are overweight, they don't do exercise, they don't eat well, you know, for sure they gonna die of cancer! I'm very energetic and I go to the gym, I dance at least ten hours a week, I work full time, I'm running all the time, and I said, "No, I don't have cancer, it's not for me." My sister thinks the same as me: "We're fine for sure." The two that we thought they were positive, they were the two [who were] negative. (FC, S)

Finally, the significance of being a carrier could also be based on an emotional relationship involving psychological identification with their mother:

> I knew it. I don't know why. I don't know. I just felt it. I don't know. I always knew I was the same thing. Me and my mom we're, I think we're the same. Physically, um, that's really weird, that's what I say. It's like, I'm exactly like my grandmother. I look like my grandmother but I don't look like my mom. But it's like we're the . . . all the same person at the same time. That's why I felt it that way. (FC, M)

To illustrate the representative differences between cultural constructions of risk awareness, the Ashkenazi Jewish participants often expressed ethnic risk awareness, which was not present in the narratives of the French Canadian women:

> You know, three daughters and I keep thinking, "Huh! I'm so glad my husband's not Jewish." As if that might improve the odds, you know. I know it doesn't really work that way. So, I'm diluting the gene pool. (AJ, S)

> There's another thing that I associate it with. I guess that it tends to be a Jewish genetic disorder, so, I think that I'm, you know, I'm, I'm very identified. My Jewish identity is very

> important to me. So, I don't know how to say this exactly, but there's something about it that it's, you know, we all come from the *shtetl* [Yiddish, meaning to designate a small town in Central or Eastern Europe with a large or exclusively Jewish community], and we all gave it to each other back somewhere, in some little Eastern European town. There's something that's kind of, almost, you know, there's something sweet about that somewhere, that it's, you know, there's, I don't know how to explain exactly that. It makes me think very much in the clan, somehow. It's interesting. It's not entirely negative to me. (AJ, S)

The French Canadian women understood a BRCA genetic risk within the family. One French Canadian woman, who was the first person in her family to undergo genetic testing, illustrated how she understood her result and the process in the context of her family, without knowing that the French Canadian population has founder mutations:

> It's a test that cost a lot. They weren't sure if I was the good candidate to go through all that. Then they did what they call another type of test, it's something to start. [The genetic counselor] explained it to me as if they gave me words to write, you know, instead of checking every word to see if I have [full gene sequencing test]. If I did it wrong, they checked a few ones, you know just a few [French Canadian, founder mutations testing]. Then, they had the result, I was negative. She [aunt] came, she was positive. Then, I had the real test and I was positive. (FC, S)

Discussion

Using qualitative, theoretically oriented, semistructured interviews in which illness narratives were the focus, we identified cultural differences and similarities between Ashkenazi Jewish and French Canadian women who had BRCA mutations and access to the same medical services. The differences observed in the conceptual and emergent themes were a coherent representation for the cultural understanding of the experience of BRCA carriers.

Undoubtedly, all participants identified their condition as genetic; however, science and medicine has a particular value in the Jewish culture, and we found the reproduction of medical facts to be the exclusive explanatory model for being a BRCA carrier among the Ashkenazi Jewish participants. The French Canadian women also valued medical knowledge; however, they often used other beliefs to explain their genetic status, which they communicated without conflict. The French Canadian participants did not experience any contradiction in having, for instance, coinheritance of physical characteristics as a lay theory of inheritance (McAllister, 2003). Some French Canadian women believed that lifestyle affects genetic status, whereas others assumed that psychological identification with a close relative carrying a BRCA mutation could provide meaning to and explanation for their genetic status. Alternative belief systems readily influenced the explanatory models that the French Canadian women used.

Many of the Ashkenazi Jewish and French Canadian women emphasized that their BRCA mutation was an embodied risk (Kavanagh & Broom, 1998), and that they were unable to explain it because "it's just there." An embodied or corporeal risk is located in the body as a physical characteristic that places a person at a risk of a future disease. It is not something that individuals can control through their lifestyle, nor is it externally imposed, as with environmental risks. The French Canadian women had particular difficulty in accepting this concept.

Historical, social, and political aspects are important determinants of knowledge in genetic studies of ethnic groups (Lock & Nguyen 2010; Rose, 2007a). Genetically, the patterns of mating and reproduction determine the structure of the human population. Historically, geographic isolation has been an important factor in genetic differentiation; further subdivisions, often corresponding to ethnic groups, can be reached depending on the degree of reproductive isolation and endogamy (Burchard et al., 2003).

According to Carmeli (2004), Jews are overrepresented in human genetic literature relative to the population size. This tendency is attributed to two factors: the perception that Jews are a genetically discreet and homogeneous group, and that they are in an accessible Jewish community. The participation of Jewish scientists has facilitated this community:

> The active involvement and leadership of same-group scientists also serves to alleviate ethical concerns of external regulatory bodies, who may take it as guarantee for project acceptability and potential benefit to the participants and the community at large. This factor is of exceptional significance given the Jews' 20th-Century history of genetic victimization. (Carmeli, 2004, p. 81)

Furthermore, the geographical proximity of large Jewish communities to large cities with major research centers, and their familiarity with genetic services, are cited as important factors. For instance, testing programs to determine the carrier status for Tay–Sachs disease have been extremely successful in both North America (Mitchell, Capua, Clow, & Scriver, 1996) and Israel (Broide, Zeigler, Eckstein, & Bach, 1993). French Canadians are also an isolated population, with at least 22 Mendelian diseases occurring at unusually high rates (Scriver, 2001). They are also highly represented in the genetic literature with regard to medical diseases (Carmeli, 2004). Despite their risk of several genetic conditions, we identified no concern that genetic risk could

be traced to cultural identity in any of the narratives of the French Canadians. Of note, there was no ethnic awareness of the specific BRCA mutations or other genetic conditions common to their heritage.

Although Ashkenazi Jews have a higher prevalence of BRCA mutations than French Canadians, to understand the significance we must consider the various social and historical determinants. Mozersky and Joseph (2010) argued,

> The correlation of genetic breast cancer with specific aspects of Jewish history means it can easily become associated with Jewish preservation and survival. An organization called Jews Against Cancer of Breast (JACOB) International is devoted to educating Ashkenazi Jewish women about their increased risk of genetic breast cancer and encouraging them to seek genetic testing in order to fulfill their mission to ". . . break the cycle of *L'DorVa-Dor* [Hebrew, "from generation to generation"] when it comes to hereditary breast and ovarian cancer . . . May we, as a Jewish people, go from strength to greater strength!!!" (JACOB International) The website explicitly associates being tested for the Ashkenazi BRCA founder mutations with the health of all future Jews. (p. 424)

Phillips et al. (2000) and Andrews et al. (2004) arrived at a similar conclusion in their research of the cultural and religious issues involved in decision making related to genetic testing among Ashkenazi Jewish women. In total, 74% of 102 Ashkenazi Jewish women in Ontario, Canada, and 78% of 60 Ashkenazi Jewish women in Sydney, Australia, reported that the "potential to improve health of [the] Jewish community" influenced their decision to be tested. In addition, this was the only factor considered meaningful to participants from both studies.

The Ashkenazi Jews and French Canadians participating in our study can be described as "ethical pioneers" (Rose, 2007b). In relation to their bodies and their choices, these women had to shape new ways of understanding, judging, and acting with experts and with others in analogous situations, particularly those to whom they owed responsibilities. According to Rose, these women were "biological citizens" who "are pioneering of a new informed ethics of the self—a set of techniques for managing everyday life in relation to a condition and in relation to expert knowledge" (2007a, p. 146).

In this cultural and historical context, we anticipate that Ashkenazi Jews are proactive, particularly within their community. As we observed, living with a BRCA mutation was a matter that automatically included family and friends and extended to their social network and the media beyond. The information exchanges led to enrichment of the experience of their community members and generation of their social and media prototypes. Furthermore, a strong sense of community among the Jewish women led to enhancement of their ethnic risk awareness and establishment of clear social prototypes as BRCA carriers. For Ashkenazi Jews, being proactive and knowledgeable about the increased risk of genetic breast cancer could be an opportunity to mobilize and take action to prevent disease for the entire community, particularly because it is associated with Jewish history and future generations (Mozersky & Joseph, 2010).

In contrast, the experience of French Canadian women as BRCA carriers was distinct in several ways. When the French Canadian participants were asked if they knew of someone with the same problem, they only referred to women with breast cancer whose genetic status was unknown. Furthermore, the genetic status was excluded in their social media prototype, which was based on women who underwent bilateral mastectomy for breast cancer. Without any social prototypes for being a BRCA carrier, the French Canadians spontaneously stated that the only other women with this health condition were at the hospital where they underwent genetic testing.

Some women who participated in the multicenter, experimental breast cancer screening program in Quebec (Proulx et al., 2009) "felt isolated and would like to see individual or group counselling" (p. 170). Although the participants in the study by Proulx et al. were diversified with regard to cancer status and knowledge of the BRCA status, it is important to emphasize that the women participating in this program considered themselves privileged because they were aware that "the reality was different for others in the current healthcare system" (p. 167). Similar findings were observed in the French Canadian narratives in our study, with women stressing the importance of accessibility to outstanding care once they were genetically tested, and stating that they valued the reassurance of being part of a special high-risk program.

Considering the French Canadian participants, some might have become the first social prototypes for their group if they shared their experience, provided testimonials, and offered support to others. Experiential knowledge related to analogical thinking is already known to be influential with respect to distinct aspects of HBOC experience (d'Agincourt-Canning, 2005; Kenen, Shapiro, Hantsoo, Friedman, & Coyne, 2007). In our study, we demonstrated how culture can affect the opportunities to communicate and exchange experiences.

Press et al. (2001) found a meaningful difference in the knowledge of BRCA testing among women in the United States according to ethnicity. Ashkenazi Jewish women had a significantly higher level of knowledge of the breast cancer genes (67%) than European American and African American women (both 43%). The authors stated that this effect was specifically related to Ashkenazi Jewish ethnicity and not to educational level.

In our study, we found a significant difference between the two ethnocultural groups in the observed length of time in the women knowing their carrier status prior to the interview. This difference might be a reflection of the historical elements involved in the testing process (Rosenblatt, Foulkes, & Narod, 1996). The availability of the genetic test, because of variations in scientific validity, might account for the observed differences, although this is a sociocontextual factor in itself. We also found a significant difference in the educational level between the two ethnocultural groups; however, how the education level could account for the divergence in ethnic risk awareness between the two groups remains unclear. For example, according to the present study findings, a range existed in the education level in both groups; yet, ethnic risk awareness was homogenous within each group. The role of the education level in relation to any of our divergent findings remains unknown because of the small sample size, which precludes our understanding and requires further research.

Of note, the Ashkenazi Jews and French Canadians in our study expressed their "biological citizenship" differently. The Ashkenazi Jewish women can be viewed as a case "par excellence" of biological citizenship as described by Rose (2007b). However, as Rose (2007b) also pointed out, groups behave differently as "biological citizens" depending on their cultural capital. According to Groleau et al. (2010), "In Quebec, ethnic identity, language and religious denomination have traditionally been closely linked if not coterminous" (p. 858). We observed a less proactive social action among French Canadian participants. We could put forth that this might be related to fatalism and resignation, which is influenced, in part, by the Catholic religion. Based on the findings of the present study, culture influences how women at risk of developing HBOC view and experience the genetic testing process and living with a BRCA mutation.

Study Limitations

The participants were recruited through a single program in Montreal, indicating that the experience of participants from other centers might differ. Further research is required to determine if the identified themes from the participants are representative of a larger group.

Issues for Clinical Practice

On the basis of the present study findings, we provide implications for physician and patient education regarding appropriate referral to and use of cancer-specific genetic services. We identified some cultural barriers in the awareness of French Canadian women regarding genetic testing and their exposure to genetic information. Without social or media prototypes and testimonials, French Canadian women lack meaningful information to help them understand the potential uses of their genetic knowledge. Preserving the joy of a moment by not discussing health matters during family gatherings hinders the development of a shared HBOC experience. With the lack of adequate awareness of their ethnic genetic risk, it is more difficult for French Canadian women to link their family history of breast and ovarian cancer and to seek medical advice, even with numerous early onset cases. Considering the Canadian public health system, it is important to investigate system-level barriers, including the perceptions of professionals and referral patterns from different medical services in Quebec.

Although the narratives of the Ashkenazi Jewish women were closer to the biomedical model, we must recognize some "otherness" in the microdynamics of the clinical encounter. The risk is to oversimplify and to engage less in understanding these other aspects. In a research study involving 256 Ashkenazi Jewish women in Australia (Apicella et al., 2006), preferences for the delivery of genetic services varied with personal characteristics and experiences. It was also identified that counseling should be tailored to be responsive to these differences. Therefore, it is imperative not to have a "one size fits all" clinical approach. "Subgroups of clients will have different preferences and perceived needs" (Apicella et al., p. 165). According to Kleinman and Benson (2006), "Anthropologists and clinicians share a common belief, i.e., the primacy of experience" (p. 1674 [PDF]). Finally, Warren (2011) proposed a change of focus toward the provision of culturally sensitive counseling:

> Rather than trying to learn everything about specific cultures, health beliefs, and religions, we can learn a little at a time, ask our clients to share relevant stories and experiences, and then listen, process, and share our learning with colleagues, students, and other professionals on our health care team. (p. 543)

Conclusions

Identification of sociocultural differences between Ashkenazi Jewish and French Canadian women in the experience of carrying a BRCA mutation is important for developing approaches to assist women in adapting to their genetic status. For example, social prototypes and genetic screening programs originating from the French Canadian community or at the governmental level might lead to further increase in the awareness about the genetic risk in this group. In contrast, Ashkenazi Jewish women might require improved access to services and information. Clinically, genetic counselors must be more attentive to the experience of individuals and to the meanings

given to genetic knowledge for providing a more culturally competent approach that best supports preventive decision making.

Based on the results of the present study, the French Canadian community could benefit from a greater awareness of an HBOC-associated risk. Genetic testing for BRCA mutations is not expensive given that relatively few specific mutations account for the majority of mutations in certain populations. Regardless of the cultural group, promoting exchanges between women who have undergone BPM and other women experiencing risk-reducing decision-making processes should be encouraged. This is particularly required for French Canadians because their social prototypes are less developed.

Based on our findings, we suggest that sociocultural aspects play an important role in the experience of French Canadian and Ashkenazi Jewish women. Further studies of the meanings given to BRCA genetic status in other cultures need to be conducted to gain additional insight. Moreover, this would ensure the use of person-centered genetic counseling approaches tailored to the background, requirements, and preferences of a woman.

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