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Original Research

The Effect of Experiential Knowledge on Construction of Risk Perception in Hereditary Breast/Ovarian Cancer

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The purpose of this study was to explore the connection between experiential knowledge of hereditary breast/ovarian cancer and understandings of personal cancer risk. Using a qualitative research design, the investigator conducted in-depth interviews with 53 individuals (45 female, 8 male) from families at high-risk for hereditary breast/ovarian cancer. Study results showed that two forms of experiential knowledge, empathetic and embodied knowledge, were integral to participants' constructions of their cancer risk. They also illustrated that knowledge derived from experience often took precedence over objective clinical estimates of risk. The paper discusses the clinical implications of these findings and suggests that counseling strategies, which expand upon patient's lived experience and knowledge of the disease, may enhance communication of genetic risk. Assessment of experiential knowledge promises to suggest new ways to frame genetic information that will enable people to better understand their objective risk or to modify exaggerated and/or inaccurate risk perceptions.

KEY WORDS: experiential knowledge; risk perception; family history; embodied and empathetic knowledge.

INTRODUCTION

Genetic testing for BRCA1/2 mutation offers persons at risk for hereditary breast/ovarian cancer new choices for managing their health. Women found to have a BRCA1/2 mutation, for example, may choose to engage in enhanced cancer surveillance or have prophylactic surgery and those found to be negative may find relief from excessive worry. Clinicians, social scientists and the public at large, however, have raised concern about the effects of genetic risk information on a person's sense of psychological as well as social well-being. Much effort has been devoted to trying to address the psycho-social consequences of genetic testing through explorations of how people perceive and live with genetic cancer risk (Bottorff *et al.*, 1998; Jacobs, 2000; Hopwood, 1998; Marteau and Lerman, 2001; Sachs *et al.*, 2001; Shaw *et al.*, 1999).

This inquiry is complex. Understanding the meanings people attribute to a genetic predisposition to cancer requires an analysis of the ways in which genetic risk information affects people individually, within their families and communities and in their social lives. It also requires further study of how information about hereditary breast/ovarian cancer risk is communicated and understood by those receiving genetic counseling. Indeed, the finding that inaccurate or exaggerated perceptions of cancer risk frequently persist after genetic counseling is of concern (Blandy *et al.*, 2003; Braithwaite *et al.*, 2004; Cull *et al.*, 1999; Evans *et al.*, 1994; Hallowell *et al.*, 1998; Lerman *et al.*, 1995; Lloyd *et al.*, 1996; Rees *et al.*, 2001; Ryan and Skinner, 1999; Watson *et al.*, 1999). While interpretation of risk involves mediation between objective estimates (numerical probabilities) and subjective

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experience, few empiric studies have examined how family history and subjective experience influences women's understanding and perception of their cancer risk (Rees *et al.*, 2001). Little attention has been paid to how risk perception is shaped by experiential knowledge: that is, different ways of living with, experiencing and knowing hereditary breast/ovarian cancer. This paper aims to address that gap.

The objective of this study is to explore the connection between experience, construction of knowledge about cancer and perceptions of cancer risk. The research presented here suggests that counseling strategies, which are grounded in patients' lived experience and knowledge of the disease, may lead to more effective communication of genetic risk.

BACKGROUND

Although epidemiological studies have identified family history as a major risk factor for breast/ovarian cancer, there has been little investigation of how family history influences women's knowledge about their cancer risk. A number of studies indicate that women with family histories of breast cancer have high levels of psychological distress and anxiety, as well as persistent and intrusive thoughts about developing breast cancer (Baider *et al.*, 1999, 2000; Hailey *et al.*, 2000; Kash *et al.*, 1992; Lerman *et al.*, 1995; Zakowski *et al.*, 1997). Other research confirms that women with a family history of breast/ovarian cancer see themselves as especially vulnerable to getting the disease (Biesecker, 1997; Chalmers and Thomson, 1996; Chalmers *et al.*, 1996; Evans *et al.*, 1993; Vernon *et al.*, 1993). Family history is further identified as shaping attitudes towards and motivations for seeking genetic testing for hereditary cancer risk. (Jacobsen *et al.*, 1997; Julian-Reynier *et al.*, 1996; Lerman *et al.*, 1995; Struewing *et al.*, 1995). Yet missing from these studies is a deeper examination of how risk perception is shaped by different ways of living with, experiencing or knowing hereditary cancer. Some recent studies have begun to address this gap.

Kenen *et al.* (2003) conducted 21 semistructured interviews with women coming to a cancer genetics clinic for the first time. They found that women used their family history and family experiences with breast/ovarian cancer as reference points in evaluating their own cancer risk and in deciding what to do. Affecting their outlook were the number of breast/ovarian cancers in the family, the positive or negative cancer experiences that close relatives had undergone as well as their past and present interpersonal relationships. Rather than statistical probabilities, women relied more on these experiences, in particular feelings of gain and loss, to interpret genetic information and guide future choices. These findings are supported by a similar study on individuals at risk for hereditary nonpolyposis colon cancer (HNPCC). McAllister (2003, 2002) found that participants understanding of cancer risk appeared to result from the individual's experience of and interpretation of this family history rather than the actual pattern of cancer within the family history (2003). Specifically, "their personal experience was what made certain aspects of the family history more salient to them in constructing an explanation of the family history that was meaningful to them" (McAllister, 2003, p. 185).

Indirect evidence also points to the importance of experiential knowledge in shaping notions of personal risk within the cancer experience. For example, Geller *et al.* (1997) conducted ten focus groups with women as part of an effort to improve models of informed consent for BRCA1/2 testing. Their purpose was to obtain a better sense of women's understanding of genetic testing, what they would want to know about testing if it were offered, and their reasons for such interest. Their findings showed that how patients understood factual information was contingent upon their background assumptions and personal history (Bernhardt *et al.*, 1997; Geller *et al.*, 1995, 1997). Stories, anecdotes and personal exposure to the disease resonated deeply in shaping women's knowledge about cancer. Further, risk perceptions constructed from these experiences with cancer were often resistant to change. Some women from the focus groups, for example, did not accept 'objective' risk estimates if they were not consistent with their family or personal experience.

Published reports also indicate that care-giving experiences can have a profound effect on how women come to know cancer. By virtue of being close to the person with cancer, a caregiver often participates in the cancer experience directly. Indeed, the literature suggests that caring for ill family members with cancer is often a source of prolonged and intense anxiety (Chalmers and Thomson, 1996; Chalmers *et al.*, 1996; Murphy, 1999; Rees *et al.*, 2001; Wellisch and Lindberg, 2000). Erblich *et al.* (2000), for example, found that women whose mothers died of breast cancer had significantly higher breast-cancer related stress than those who did not. Further, those who had taken care of their mothers had higher levels of distress still.

The loss of a mother in relation to developmental stage may also have bearing on how women come to know cancer and from that develop perceptions of personal cancer risk. Work by Hopwood *et al.* (2001), for example, illustrates that women who experienced the death of a mother from breast cancer between the ages of 10 and 20 had a higher degree of cancer worry than women who were bereaved in adulthood. Perceived vulnerability to cancer was linked to this adolescent experience and whether or not the woman's mother survived (Hopwood, 2001). Along similar lines, Chalmers and Thomson (1996) found that closeness of relationship and differences in the illness trajectory influence how people caring for family members with breast cancer perceive the illness. Those who experienced unpredictable or erratic illness paths (e.g., cancers unresponsive to treatment) often saw cancer as a greater threat to themselves and others, than those whose relatives responded well to treatment or had long, stable periods of remission. This observation is further supported by other studies, which show that family members often experience as much psychological distress as the individual who had cancer (Baider and De-Nour, 2000; Weihs and Reis, 2000). Moreover, Rees *et al.* (2001) suggest these experiences may be more stressful if a person attending to the relative is aware of her own risk of developing the disease.

The concept of experiential knowledge may be useful to understanding some of these findings. Locating knowledge in everyday experiences, theorists have called attention how individuals use experiential knowledge, together with 'objective' forms, to interpret and respond to life events (Babbit, 1993; Code, 1991; Harding, 1993; Smith, 1987). As Code (1993) so aptly states, knowledge is not just an abstract product based on rationality and objective determination of truth, but is a process that emerges and is shaped by the identity, circumstances, experiences, and interests of the knower. Experiential knowledge acknowledges the kinds of knowing that arises from everyday lived and interpersonal experiences (Code, 1991). Experiential knowledge is not merely perception, feeling or belief but involves an intricate interaction of conscious and unconscious knowing, of objective and subjective knowledge, of empathy and reflection (Dalmiya and Alcoff, 1993). While the concept of experiential knowledge has been widely discussed in the philosophy, ethics and social science literature, to my knowledge it has received less attention in genetic counseling.

This work is based on the premise that experience with cancer leads to certain kinds of knowledge about the condition, which in turn contributes to and shapes risk perception regarding cancer risk. The research does not ask whether this experiential knowledge is scientifically accurate. Rather, it centers on the question how is hereditary breast/ovarian cancer experienced and known? I follow Abel and Browner's (1998) lead in categorizing experiential knowledge into two broad types: (a) empathetic knowledge and (b) embodied knowledge. 'Empathetic knowledge' is characterized as knowledge derived from close associations or emotionalties with others experiencing a particular event (Abel and Browner, 1998). Empathetic knowledge enables individuals to give validity to their own understanding of disease, which has been generated by connectedness to and knowledge of other family members' experiences. Embodied knowledge, on the other hand, refers to subjective knowledge derived from bodily experience (Abel and Browner, 1998), in this case of having breast/ovarian cancer oneself. In the context of hereditary cancer, however, it is important to note the overlap between these two kinds of experiential knowledge. For example, a woman might come to know cancer through a relative's experience as well as having the disease herself (empathetic and embodied knowledge). Thus, perceptions of risk for future disease are grounded in knowledge gained from personal illness as well as connectedness to others who have had the disease. These categories are not used to set limitations on knowing, but to provide an orientation and understanding of the complex ways in which cancer is experienced and may come to be known in the family. They also lay the groundwork to consider how experience and knowledge of hereditary cancer affects how people interpret and respond to cancer risk information provided by genetic counselors.

METHODS

Recruitment

The work reported here was part of a larger ethnographic study designed to acquire a deeper understanding of women's moral and social experiences with genetic testing for hereditary breast and/or ovarian (d'Agincourt-Canning, 2003). In contrast to research methods which focus on people's behavior, without regard for what such behavior means to those engaged in it, ethnography is committed to trying to

understand the meanings people make of their experiences (Emerson *et al.*, 1995, p. 12). Ethnographic analysis is an iterative process that involves developing categories and conceptual themes and discussing, verifying and extending these with participants (Hammersley and Atkinson, 1995; Huberman and Miles, 1994). At the same time, it seeks to ground emerging analytic themes within the historical, cultural and social context of people's lives (Britzman, 1991; Lock and Kaufert, 1998).

In this study, data were derived from individual interviews and field observations collected from 1998 to 2001, after evaluation and approval by the UBC research ethics committee. Participants were initially recruited through the Hereditary Cancer Program (HCP) at the BC Cancer Agency, Vancouver, where they had been referred to receive genetic counseling for breast/ovarian cancer because of their personal and/or family histories of the disease. It is important to note that due to the HCPs eligibility criteria, only individuals and families with an extensive family history of breast/ovarian cancer were offered testing.[3] These participants then aided further recruitment by contacting other family members who were eligible for or considering genetic testing. Beeson and Doksum (2001) call this form of sampling, 'cascade sampling.' It begins with the 'index' person or carrier and having them refer the researcher to other biological relatives or significant others. Fifty-nine people were approached and six either declined to participate or did not respond to a letter or phone call of invitation. Those who declined gave no reason for their decision. The final sample comprised 53 persons (45 women and 8 men).

Sample Characteristics

Demographics

Table I shows the demographic characteristics. Participants ranged in age from their early 20s to over 60. The majorities were married and had children. Educational background varied: 38% had completed high school and 49% had obtained further vocational training or university.

Table I. Study Cohort: Demographic Profile

Category	Information
Sex	
Female	45
Male	8
Age	
20–30	6
31–40	13
41–50	17
51–60	11
61–70	6
Marital status	
Single	10
Married	32
Common-law	2
Separated/divorced	8
Widow	1
Number of offspring	
None	17
One	7
Two	11
Three	7
Four	7
Five	2
More than five	2
Level of education	
<High school	3
High school diploma	20
Diploma/technical school	16
University	10
Unknown	4
Employment status	
Working full-time	30
Working part-time	6
Self-employed in the home	3
Unemployed	4
Retired	7
On leave	3

Genetic Testing and Cancer Status

Table II shows further details of the participants involved in the study: 39 underwent testing; 6 declined testing even though they met eligibility criteria; three participants from the same family (1 with breast cancer, 2 without) had sought testing but were waiting for the index test results. Fourteen of the women who sought BRCA1/2 testing had already been affected by breast or ovarian cancer; the remainder were cancer-free but considered at high-risk based on family history. In addition, the investigator interviewed 4 spouses and 1 son of an individual who underwent testing. Table III provides information on the participants' test results: Of the 38 participants who underwent testing, 28 (25 females, 3 males) received positive test results and 11 (9 females, 2 males) were

[3]See the following website for the BCCA Hereditary Cancer Program's specific referral criteria: http://www.bccancer.bc.ca/HPI/CancerManagementGuidelines/HereditaryCancerProgram/ReferralInformation.

Table II. Genetic Testing for BRCA1/2 Mutations

Participant categories	Female affected[a]	Female unaffected[b]	Male	Total
Received genetic testing/results	14	20	5	39
Declined testing	2	4		6
Awaiting index test results[c]	1	2	1	4
Family members, not eligible for testing[d]	2		2	4

[a] Women who had been affected by breast/ovarian cancer.
[b] Women who did not have breast/ovarian cancer.
[c] This family was awaiting test results from the index case, that is the person affected with breast cancer, before further genetic testing could proceed.
[d] Participants in this group were spouses or partners of those who were tested, and thus not eligible for testing.

negative for BRCA1 and BRCA2 mutations. Participants who tested negative were true negatives; that is, they did not carry a previously identified family mutation.

Data Collection and Analysis

In-depth interviews comprised the core of this research. With few exceptions, the interviews were conducted in the participant's homes or another place of their choosing. Participants lived in various locales throughout British Columbia, including rural and nonurban regions. In addition, two participants were interviewed by phone. The interviews ranged from half an hour to 2 hr in length. They covered a range of topics, including participants' family and personal history with breast/ovarian cancer, their reasons for seeking testing, their experiences with genetic counseling and testing; and the impact that genetic test information had on their life. The interviews were tape-recorded with prior consent of all participants and transcribed verbatim. The transcripts were content analyzed by the investigator and interview segments grouped into predefined categories based on interview questions (e.g., family history, experiences with cancer, and personal understanding of risk). Comparison of categories within and between interviews (as well as field notes and reflective inquiry) enabled further clarification of meanings, relationships, and conceptual themes (Hammersley and Atkinson, 1995; Huberman and Miles, 1994; Strauss and Corbain, 1990). Narrative accounts about specific situations concerning these themes are presented in the following section.

Table III. Genetic Test Results for BRCA1/2 Mutations

Category	Female affected[a]	Female unaffected[b]	Male	Total
Identified BRCA1/2 mutation	13	12	3	28
No mutation	1	8	2	11

[a] Women who had been affected by breast/ovarian cancer.
[b] Women who did not have breast/ovarian cancer.

RESULTS

Results are organized into three sections: (A) Empathetic knowledge; (B) Embodied knowledge; and (C) Risk perception. All participants have been given pseudonyms to protect their anonymity.

Empathetic Knowledge

Empathetic knowledge—that is, knowledge derived from associations with others—appeared to exist along a continuum from weakly held to strongly held convictions about cancer based on close ties with others. Thematic analysis further revealed four broad patterns of empathetic knowledge: tangible knowing, recent knowing, distant knowing, and accidental knowing. Tangible knowing referred to subjective knowledge derived from close associations and personal experiences with people suffering from breast/ovarian cancer. It also included strong awareness of the family history of the disease. Recent knowing (a subset of tangible knowing) also encompassed knowledge as derived from observing the experiences of others, but referred to cancer knowledge of cancer as something new to the family. Distant knowing referred to knowledge of familial cancer obtained solely through discussion and stories about other family members. Accidental knowing signified knowledge of familial cancer obtained by chance. Each of these is explored in turn.

Tangible Knowing

Tangible knowing included the largest group of participants. Of the 53 participants, over two-thirds ($n = 39$) came to genetic testing aware of their strong family history of the disease. This was obtained in different ways. For the majority of participants, however, these histories included living with someone

with breast cancer or witnessing the death of relatives. Lorraine's story is typical in this regard.

> My Auntie P. who married my dad's brother, was the first one in that family to get diagnosed with cancer and she died of breast cancer at the age of 37. Then, the next sister was Auntie F. She had breast and ovarian cancer, I believe, and she was 47. Then mom's younger brother, Uncle J. got diagnosed with a brain tumor, and he was about age 50 when he died. So it always seemed like we were going to funerals and people were sick when I was a kid growing up . . . And then about 5 years ago now, my mother, well she died about 5 years ago, but she was diagnosed 6 years before she died with ovarian cancer. So she had surgery, and then she had chemo, and then she had chemo again . . . I took time off work and looked after her for about 3 months with my father. She died at home.

Several times during our interview Lorraine recollected how cancer was part and parcel of her childhood.

> I mean I remember that as a kid thinking you know, who's next? When does this ever stop? And I had friends in school who you know when we were getting into high school and that we talked about things and they had never been to a funeral and it's like you've never been to a funeral? I mean we go all the time. It used to seem like that.

Indeed, many participants had difficulty in distinguishing clearly the age at which they first learned about the existence of cancer in the family. It was just something that was always there. Brenda, who is now in her late 40s, recounted this kind of history. Although she did not think about it much as a child, she had an awareness of the disease as always being part of the family legacy. Her family linked her to a particular past, present, and future in which cancer played a central role.

> I had like three or four aunts die of cancer when I was really quite young. I remember that they were sick. I didn't really fully understand what cancer was but I knew that was why they were dying. And then, um, so, at a very young age we knew that there was cancer, a lot of cancer in our family. And then when my mom, um, got cancer, uh, then it was really close to home. My sister had cancer in her breasts . . . when she was 30 . . . And then my, more recently, my cousin passed away and it was, uh, she started with breast cancer and another cousin got breast cancer. And it was just everywhere. Everywhere we looked it was so prevalent. So [I've been] very aware of it since a very young age.

In addition to being aware of their family cancer history at an early age, many of the women interviewed had provided care for mothers or other family members who had the disease. These women drew on experiences of caring for others to construct knowledge about breast cancer and the course it might take in their own lives. The more complex the path of the illness, the more difficult the lived experiences became. The challenges of a complex path are reflected in Nancy's words. She was in her 20s when her older sister was first diagnosed with cancer. Her mother developed ovarian cancer soon after and struggled with a difficult course.

> I think my sister was the first to have cancer that I knew of. I think she was about 32 at that point and it was really scary . . . And then mom got cancer. She was like my best friend and it was to hard to take, I guess because I was there everyday for 3 years . . . The worse thing was your hopes going up and then getting crushed. Like they always gave you good news and it was always followed by bad news, you know. So for 3 years, it was just the yo-yo, you know, the emotional yo-yo.

In addition to the number of affected relatives, other participants' recollections were shaped by what they perceived as the relentless progression of the disease trajectory. Gillian's initial awareness of cancer began with her mother's diagnosis of breast cancer, although she did not think of it as a family disease until both her aunt and sister were diagnosed with breast cancer several years later. Her mother's first cancer was treated with a lumpectomy. Several years later, however, she developed breast cancer in her other breast. She elected to have a double mastectomy at which time a third cancer was found behind the lumpectomy scar. This was quickly followed by two episodes of ovarian cancer. As a result of observing her mother, Gillian views cancer as a disease that is unyielding. Her mother's experience has also made her concerned about her own risk.

> I was just really scared because I thought, gees, it is so relentless. You know, this cancer is just, won't go away. . . . I was just really scared for her, but also, like, angry, you know, why, why it just won't stop. And also then I, I got nervous about myself like, you know, what my risks were. They're pretty high.

As this comment suggests, Gillian drew on her mother's experiences to construct knowledge about cancer. Cancer became a very real threat not only to her mother, but to herself as well. She incorporated her mother's experiences into her own evolving sense of risk. Her sense of future self included fatalistic notions of the disease.

Recent Knowing

The extent to which individuals are aware of hereditary conditions depends not only on communication within the family, but also on the temporal course of cancer within the family (Richards, 1996). Recent knowing is in fact a subcategory of tangible knowing. Both are based on knowledge of the family's cancer history, but the difference is in when cancer becomes known to be an inherited family condition. Indeed, for Kate, knowledge that cancer 'ran in the family' was a new discovery. Up until her generation, the family apparently had been cancer-free. Both her mother and father, although elderly, were in relatively good health. Grandparents and older relatives had died of unknown or unrelated causes. There was no documented diagnosis of breast cancer in either immediate or extended family. Thus, the issue of hereditary risk did not arise until two of her four sisters developed breast cancer. Her older sister was diagnosed with breast cancer at the age of 43 and her younger sister at age 39. Kate was in her early 40s at the time.

> Oh, I must say, I really didn't think that much about it when Margaret was diagnosed, but when Kim was diagnosed, like the first thing that comes to your mind is WHO'S NEXT?[4]

Recent knowing overlaps with tangible knowing in that both are derived from experiences with particular others. Yet, in comparison to those who described cancer as something that was always there, the latter example illustrates knowledge of cancer as something new to the family. Up until her sisters' diagnoses, Kate attached no meaning to cancer other than it was a frightening, life-threatening disease. Her sisters' illnesses impelled her to reevaluate the implications of the disease for her family. Because of their experiences, she began to think about the place that cancer might have in her own life and the lives of other family members. Thus, Kate, like other participants, turned to subjective experience and family history of cancer (past, present, and ongoing) in constructing her knowledge of cancer, cancer as a family illness and personal risk identity. Media reports and her job as a lab technician in a local hospital also supplemented the development of her ongoing knowledge.

[4]Capitals are used to illustrate the emphasis participants placed on certain words.

Distant Knowing

For a few women, familial histories of cancer were distant and known solely through family discussions. Indeed, Marilyn was typical of those who recalled having an early, but less tangible, knowledge of her family's history of cancer. Her grandmother had died from breast cancer at a young age, long before Marilyn was born. She had also been told that two aunts had died from breast and/or ovarian cancer, but did not know either of them personally. Never having lived with someone who had breast or ovarian cancer, she felt removed from the familial cancer experience. Nonetheless, Marilyn like many participants feared cancer. She drew on popular discourse and social representations of cancer to construct her beliefs about the disease (Kasper and Ferguson, 2000; Potts, 2000).

> I don't know I've always been scared of cancer for some reason, but not because of family or anything like that, it's just always, I probably just thought it was horrible. Like something you would never want to have. It seems like it's all over and [there are] terrible stories about it.

Accidental Knowing: Learning by Chance

One participant learned about her family history purely by chance. Sara's parents had divorced when she was very young and her mother had lost contact with her father's side of the family. Long after Sara had left home, her mother met her former husband's cousin at a local store. They recognized each other, and the cousin, who had been tested for the BRCA1 mutation, told her about the program. The cousin, through Sara's mother, invited Sara to participate. This was the first Sara had ever heard about either genetic testing or the family history of the breast and ovarian cancer. Several times during our interview, she spoke about how this discovery disturbed her.

> The thing that was scarier I think than anything, is that you realize, look at all these family members that I don't even *know*. I have been so removed from that side of the family. So that was kind of disturbing because you think it is sad in a way that you know we weren't in touch with all these people, or that there wasn't anymore communication. . . . Maybe when all these people were being diagnosed because of some of the ages or the I think it was just overwhelming to sort of for me, to sort of realize that hey, there's all these people that I am related to, all of the sudden there is this realization that something's happening in the family and it could have affected me or could affect me. And I didn't have a clue about it . . . And

> I do realize that because even with my dad and his parents and stuff there was a lack of communication, so I can see why it happened. But it is kind of frightening when you look on paper at all these people and you're going wow, I don't even *know* them.

Whether intended or not, a genetic test yields results that extend beyond the individual, affecting all members of a shared biological descent. Sara's words suggest that her concern for getting cancer was made more difficult by the lack of communication with family members and uncertainty about her past. She lived her life divorced from these other family members and unaware of her family's history of cancer. In learning about this history, Sara was compelled to renegotiate her identity both in terms of a new-found family and knowledge about a disease for which she was at risk.

Embodied Knowledge

While the previous group of women used primarily family history, the experiences of caring for others, and family stories to construct their understandings and knowledge of cancer, others drew on their embodied knowledge. Embodied knowledge is defined as knowledge gained from subjective experiences with cancer and cancer treatment. This group is distinguished from the other participants by having had cancer already and by being patients themselves. Of the 34 female participants who elected to have genetic testing for hereditary breast/ovarian cancer, 14 had been previously diagnosed with breast cancer. Because of their family histories, many were not surprised when they received their diagnosis. Some, in fact, lived their lives thinking that cancer was inevitable. As Marlee put it:

> I was diagnosed at 33, just before I turned 34 with breast cancer. And I guess I always thought I was going to get it. Just because I'm so much like my mom I always thought I'd have to face it 1 day, but not so young.

Participants' embodied knowledge typically began with the diagnosis of breast cancer. Some participants found the lump themselves. For others, detection occurred during a clinical exam and for others still, by mammography. Embodied knowledge was influenced by disease extent (localized disease vs. lymph node involvement) and the effect of cancer therapy on women's bodies. Women reported diverse physiologic responses to their cancer and cancer treatment. Similar to other studies in the breast cancer literature (Potts, 2000; Saywell *et al.*, 2000), some women talked about hair loss (following chemotherapy) as being a direct challenge to their experience of self. In the following account, Laura explains how hair loss was especially difficult for her. It rendered her body unrecognizable to herself.

> What I found the most difficult was the loss of hair you know. You are talking eyebrows, eyelashes so basically you look very alien to yourself, right? So there's lots to deal with, you know, your physical appearance has changed so much.

Complications related to surgery posed a challenge for others. Indeed, Margaret talked at length about the impact that lymphedema (resulting from axillary node dissection) had made on her life.

> I have had a fair bit of trouble with is lymphedema . . . and my quality of life has somewhat changed. I mean I used to be the one that mowed the lawn and we used to have a huge garden where that camper sits right to the back here. And I remember coming home from physio and saying to [my husband] that the physiotherapist said like I shouldn't be doing that hard of work with my lymphedema and the heat. So we planted cement. That was a little hard to take.

The comment above illustrates how the physical reality of the body is integral to daily life, agency and self-identity as well as how individuals construct knowledge about the effects of a particular disease.

In the context of hereditary cancer, however, it is important to point out that individuals may draw on both empathetic and embodied experiences in constructing their knowledge of cancer. For example, a woman might come to know cancer through a relative's experience as well as having the disease herself. Linked to family history, a person's embodied knowledge of cancer may gain further significance from what has gone before it and what it implies for the future. The following narrative helps illustrate this point. Sandra, who was diagnosed with breast cancer at age 37, referred to both embodied and empathetic knowledge in guiding her decision to obtain BRCA1/2 testing.

> You know having gone through that [breast cancer] it was easy to make the decision that I didn't want to do it again and take that chance. And I think seeing that my mom had it [breast cancer] twice and that my aunt [breast cancer] had it twice, only reassured me that I was making the right decision to get tested.

Risk Perception

For most individuals in this study, cancer evoked a common story and shared identity that connected the individual self to others. Perceptions of risk for future disease were grounded in knowledge gained from personal illness as well as the experience of others. There existed a "burden of anticipation" (Wexler, 1979) based on embodied experience as well the family legacy of breast cancer. This knowledge of shared identity also had implications about cancer risk for daughters, granddaughters and future family. Without exception, all mothers diagnosed with breast/ovarian cancer expressed concern that their children were now at increased risk. Concern was frequently raised about risk for siblings and other family members as well. In the following passage, Anna, who had breast cancer at age 47, spoke about the traumatic legacy she has left her daughter.

> You know, my daughter said to me, this is the saddest thing, "mom it seems like one woman in every generation of our family dies of breast cancer, and I'm the only woman in this generation, so I guess it will be me." So, you know, this picture of my grandmother, to my mother, to me, to [my daughter], was like: "Oh, God!"

Participants who were cancer-free drew on the experiences of other family members to construct perceptions of whether or how cancer might affect them. Just as their knowledge about breast cancer was shaped by family history and caring for loved ones with the disease, so too were their beliefs about personal cancer risk. Participants used their experiential knowledge as a basis for constructing risk identities. Vulnerabilities were triggered by knowledge gained through connectedness to others and by personalizing life experiences of family members affected by the disease. For example, following her mother's death and sister's diagnosis and experience of breast cancer treatment, Nancy began to worry excessively about her own risk. She asked her doctor for monthly clinical breast exams. She checked herself compulsively—at least once and sometimes more over the course of a day—for breast lumps and decided to have prophylactic surgery.

> When [my sister] got cancer that was so tough. She was at work with me and watching her hair come out and what she was going through was so hard to take. That made me decide that while I had all my strength, I was going to do anything I could and remove any part of my body that I HAD TO and have the STRENGTH TO FIGHT and get better after the surgeries than [go] what she went through with no strength left after chemotherapy. It just drained her.

Similarly, Jan's fear of breast cancer was grounded in the experience and knowledge of others. From the time she could remember, her mother was worried about dying from breast cancer. Her grandmother, two aunts and a number of cousins had struggled with and/or died from the disease. Jan had chided her mother about her concerns, told her just to live her life and stop worrying about developing the disease. Eventually, however, Jan's mother was found to have breast cancer. At this point, Jan became aware of the amount of anxiety she herself harbored about the disease and how vulnerable she felt. Her mother's fear had become her own.

> There were a couple of my friends who also had got a diagnosis of breast cancer around the same time. And a friend my age who died of AIDS, which was of course not the same thing, but a woman I knew well dying young. I began to imagine I had a lump. And I thought this is exactly what I told my mother not to do. And I could kind of visualize it growing in my left breast and I knew that wasn't a smart thing to do. So I went to a therapist I knew . . . that helped a lot and I would say I stopped obsessing about it, but it probably remained an underlying concern and maybe even a conviction that like my mother, I decided that was how I would die.

Jan's comments illustrate that the knowledge she gained from direct experience came not only from the family, but from close friends struggling with illness as well.

Others approached their family legacy with far less fear. Sheila, for instance, recognized that she was at high risk for breast cancer. Her mother, sister and other relatives had been afflicted with the disease. However, in contrast to participants who witnessed the devastation of progressive breast cancer, Sheila's knowledge of breast cancer was shaped by a mother and sister who responded well to treatment. Sheila, like the other participants, emphasized subjective experience and family history of cancer (past, present, and ongoing) in constructing her knowledge and personal risk identity. Yet, as the following quotes illustrate, she did not struggle with thoughts and emotions about death but saw a possibility of control. Because of a particular family history and experience, she held hope for the future, even though she thought her chances of developing cancer are very high.

> If I were to be diagnosed with breast cancer tomorrow, not a whole lot would change. We would deal

> with it. We would be inconvenienced and hopefully I would end up with more hair than I have now (laughter), but that's it.
>
> I'm not shutting my eyes. I am already assuming that I am in the 90% [risk category]. . . . It's not weighing me down because I won't/it's not in me to have that happen. I got too much living to do to worry about dying.

The age at which close family members were first diagnosed with cancer acquired particular salience for some participants. They worried more and their sense of vulnerability increased as they neared the age when others in their family developed cancer. Susan spoke about this several times during our interview.

> I was really getting worried and because I was coming up to 30 and that's when it all had happened for my mom as well, so that really scared me. I just wanted to know if there was something I could do because of the history in my family. Does that mean I'm going to get it?

Interestingly, this sense of vulnerability was not held exclusively by women. Although male participants did not fear breast or ovarian cancer per se, they did express concern about developing some form of cancer around the same age that a close relative had it. Ross was 14 years old when his mother died of breast cancer. In response to the question, did he ever worry about getting cancer himself, he said:

> My mom was sick was for quite a while but played quite an important role in our lives when we were younger. And there is probably hardly a day that goes by that you don't think about her . . . I guess you asked the question did I worry about it at times? Well I guess the period of worrying about it was when my children were young and I was the age of my mother when she died and thinking you know God, what she went through with three boys and knowing that she was dying of cancer. Like I guess that is a time where you start to worry about it. . .

For most study participants, breast/ovarian cancer posed a real physical threat to their health, their bodies and sense of future self. On the basis of lived experience, many equated breast or ovarian cancer with death. The notion that death from breast cancer is inevitable may reflect, in part, the historical reality of the disease before more successful treatments became available (Rosenbaum and Roos, 2000). It also reflects the concrete lived reality that most participants had faced and as such, frequently overrode scientific knowledge about the disease. Lorraine, who was diagnosed with breast cancer at age 47 and a public health nurse, explained it this way.

> The survival rate [from breast cancer] is really good and they [physicians] are quite confident if they find it early people survive. It's just in our family that was never our experience. Everybody who got it died quite quickly actually . . . Aunty M. and Aunty E. it seemed like within a year or two after diagnosis they had both died. So my experience, my family's experience, isn't that you do well and you survive.

DISCUSSION

This study illustrates that individuals' knowledge of familial breast/ovarian cancer is shaped by family patterns of inheritance, personal observation and the experience of caring for others. The proportion of family members diagnosed with breast/ovarian cancer, how many died as well the number of times it occurred in one individual, also contribute to knowledge of the disease. While the vast majority of participants had close or frequent contact with someone who had the disease, a small minority came to know cancer and their family history of cancer as a recent event or through less direct means. Others came to know cancer by having the disease themselves.

In their paper, "Selective compliance with biomedical authority," Abel and Browner (1998) discuss two types of experiential knowledge: embodied and empathetic knowledge. They define embodied knowledge as knowledge derived from embodied experience (in their study, pregnancy) and empathetic knowledge as derived from close contact or emotionalties with individuals engaged in a particular experience (e.g., care-giving). These two forms of experiential knowledge are evident in the present study as well. Here embodied knowledge refers to women's actual physical and emotional experiences with breast/ovarian cancer and knowledge gained by living with the disease. Empathetic knowledge is acquired by living with or having close contact with others who have a particular illness. Keller (1985) describes empathy as "a form of knowledge of other persons that draws explicitly on the commonality of feelings and experiences in order to enrich one's understanding of another in his or her own right" (p. 117).

In this study, family members acquired empathetic knowledge of cancer, its particular manifestations, the side-effects of treatment and the likelihood of survival, from personal experiences in living with or caring for relatives who have had the disease. This paper also expands the concept to include knowledge

that is acquired about particular others through less direct means. For example, some participants came to know cancer through family stories passed down from one generation to the next. Although far less personal, this form of empathetic knowledge may also be important in shaping meanings about hereditary cancer. It may give rise to distinctive vulnerabilities (personal constructions of risk) that come from being part of this group

The findings here support other studies indicating that lived experience, family history and stories about family history play a key role in how individuals from hereditary cancer families construct perceptions of personal cancer risk (Kenen, *et al.*, 2003, 2004; McAllister, 2002, 2003; Sachs, 1999). McAllister (2002, 2003) and Kenen *et al.* (2003) present two theoretical models to explain how this might occur. McAllister proposes that the development of risk perception may be explained by engagement, "that is the degree of cognitive and emotional involvements with one's increased risk of developing cancer as a result of one's family history of cancer" (2001, p. 180). Engagement may be partial (at the cognitive level only) or intense (at cognitive and emotional levels), but each involves knowledge and interpretation of family history. Kenen *et al.* (2003) refer to prospect theory in their discussion of risk perception. Prospect theory emphasizes that an individual's decision under uncertainty are influenced by their own evaluation of the outcomes, which in turn depend on experience and context (Kahneman and Tversky, 1979). They propose, for example, that a woman from a hereditary breast/ovarian cancer family is more likely to rely on her subjective feelings of gain and loss, than statistic probability, when making decisions about genetic testing. The concept of experiential knowledge links with these models in that it provides some explanation for how hereditary cancer is known. As Sachs (1999, p. 739) puts it, "The family's past health history is a trajectory for future health risks." In other words, experiential knowledge may serve as the basis from which risk perception is derived.

Although the characterization of experiential knowledge as empathetic and embodied serves a useful heuristic function, clearly the distinction is not rigid. Empathetic knowledge may shape how embodied knowledge is interpreted and vice versa. Embodied experience of cancer may be influenced by previous empathetic experience of how the disease played out in family members. The two are often intertwined as they contribute to experiential knowledge and perception that extends across generations and evolves over time. Further, neither category is static and may be revised to reflect insights gained from new experiences. For example, although Marlee expected to get cancer at some point, she did not expect to develop it at such a young age. Based on her experience, her family legacy has been revised to include the knowledge that cancer can occur in young women. In the future, less toxic and more successful treatments may also change the way cancer is experienced and perceived. McAllister (2003) makes a similar observation for hereditary colon cancer families, reporting that risk perception is not static, but may change with time and events in family life.

Empathetic and embodied knowledge may lead to markedly different perceptions about cancer risk and severity, depending on what has happened in a particular family. As can be seen from the participants' accounts, this varies greatly. For some people in this study, empathetic knowledge means living with a person who has cancer or who has died from cancer (tangible knowing). It is affected by the kind and amount of shared experiences with relatives, the variability of a relative's illness trajectory, the extent of suffering witnessed and the sheer number of family members who have died from the disease. For others, knowledge of cancer is solely a matter of what has been shared through family stories and hearsay (distant knowing). There has been little or no contact with the people who have had the disease. Although these participants possess knowledge of their family legacy, it is far less personal. One participant came to know her family legacy solely by accident (accidental knowing). Likewise, embodied knowledge can take different forms. In this study, participants had breast cancers ranging from stage 1 disease to terminal illness. Clearly, this would lead to different experiences and constructions of embodied knowledge and also what others would see (empathetic knowledge). Although some might view embodied knowledge as more valid, empathetic knowledge can be just as poignant particularly in the case of hereditary cancer. The intensity of that knowledge derives from the fact it is grounded in relationships. As many participants articulated, the situation of having one's sister, mother, grandmother suffer from breast/ovarian cancer is a traumatic one. Watching the pain, misery and suffering of others is emotional and extremely difficult. Living with a mother and two sisters who suffered from cancer and the effects of treatment, for example, had a profound impact on how Nancy viewed her personal risk and sense of future, which in turn influenced her decision to seek prophylactic surgery.

This paper has focused on the familial context of knowledge production, but it is important to recognize that individuals' experiential knowledge of cancer is also shaped by external knowledge. Knowledge about the disease develops within a broader community–social, cultural and medical—that views the illness in a certain way. Although I have not examined this in depth, Marilyn's comments illustrated the influence of social discourse and representations of cancer on her understandings of the disease. *"I don't know, I've always been scared of cancer for some reason, but not because of family or anything like that, it's just always, I probably just thought it was horrible. Like something you would never want to have. It seems like it's all over and terrible stories about it."* Kasper and Ferguson (2000), Potts (2000) and Saywell *et al.* (2000) also discuss how medical and popular discourse has shaped social representations of this disease.

Practice Implications

What implications do these findings have on the genetic counseling process or information delivered during genetic counseling? This study provides empirical data validating what many counselors have determined through clinical practice; that is, "clients' perceptions of their cancer risks often depend more on their emotional well-being and life experiences than on their numerical risks" (Schneider, 2002, p. 207). The concept of experiential knowledge helps explain why some individuals from hereditary cancer may hold contradictory or non-Mendelian perceptions of genetic risk even after receiving genetic counseling. Thus, assessment of experiential knowledge suggests a useful technique to expand upon during a genetic counseling session.

Constructivism has become a major organizing framework in curriculum design and educational practice (BC Ministry of Education, 1989; 1990). At the heart of this concept lies the premise that "knowledge does not reflect an 'objective' ontological reality exclusively, but an ordering and organization of a world constituted by our own experience" (von Glaserfeld, 1984, p. 24). In practical terms, constructivism views the experience of the learner as key to the teaching-learning enterprise (Roychoudhury *et al.*, 1995). Constructivism states that knowledge is not passively received, but built upon the experience the person brings to the educational/information setting. Thus, education is promoted and knowledge constructed by connecting new concepts or information to experience and reflecting on those experiences together with the new information.

To a large extent, a constructivist approach reflects what genetic counselors already do in counseling patients for hereditary cancer disorders. A key component of genetic counseling is to ascertain a patient's understanding of her/his risk status (Schneider, 2002). Building upon this strategy, however, counseling practice might benefit from an additional exploration of the client's experience. This means that in addition to collecting and interpreting family history, genetic counselors would probe more deeply about their clients' experiential knowledge. This kind of discussion would include topics such as: How do you think about cancer given your family history? Were you involved in care-taking? Do you see breast/ovarian cancer as a disease from which one survives? How do you see cancer in terms of yourself?

An exploration of individual experience, as well as sensitivity to different ways of knowing, promises to aid counselors in assessing how people from hereditary cancer families think about and internalize genetic risk information. Counselors who explore these experiences could more directly address the factors that contribute to exaggerated or misleading perceptions of risk. For example, the present and other studies suggest women who have directly cared for relatives (in particular mothers) who have died from the disease, tend to view themselves as being at very high risk for cancer (Chalmers and Thomson, 1996; Erblich *et al.*, 2000; Zakwoski, 1997). Knowledge of this may be helpful in developing counseling strategies specifically targeted to these high-risk perspectives. By linking numerical risk estimates to a patient's experiences, and acknowledging the impact these experiences have in shaping the individual's perception, counselors may aid a patient to think through and reflect on those experiences in light of the new information. It is upon that basis that constructivist learning may take place. An exploration of empathetic and embodied knowledge with clients may also help counselors identify individuals who are at greater risk for severe anxiety, depression or other manifestation of psychological distress and would benefit from further psychological support.

However, this kind of discussion takes time. If in-person or face-to-face counseling time is limited, issues related to experiential knowledge could possibly be explored in a group session. Another suggestion might be to provide medical information on a CD ROM or computer disc for those who have the technology, which would give the genetic counselor

and the client additional time to discuss experiential issues.

CONCLUSIONS

To conclude, this paper illustrates empirically the connections between personal and family history, relationships and knowledge claims, on the one hand, and constructions of risk, on the other. It illustrates that experiential knowledge about hereditary breast cancer is derived from different ways of living with and knowing breast cancer. Most of these are connected to strong family histories of the disease, but some are not. Understanding a client's experiential knowledge begins to give a sense of how she or he may view themselves in terms of hereditary or familial risk. The work presented here suggests that counseling strategies, which expand upon patients' lived experience and knowledge of the disease, may enhance communication of genetic risk. Assessment of experiential knowledge promises to suggest new ways to frame genetic information that will enable people to better understand their objective risk or to modify exaggerated and/or inaccurate risk perceptions.

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