Preserving the Self: The Process of Decision Making About Hereditary Breast Cancer and Ovarian Cancer Risk Reduction

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Abstract

Women who carry BRCA1 or BRCA2 (BRCA1/2) gene mutations have up to an 88% lifetime risk of breast cancer and up to a 65% lifetime risk of ovarian cancer. Strategies to address these risks include cancer screening and risk-reducing surgery (i.e., mastectomy and salpingo-oophorectomy). We conducted a grounded theory study with 22 BRCA1/2 mutation-carrier women to understand how women make decisions about these risk-reducing strategies. Preserving the self was the overarching decision-making process evident in the participants' descriptions. This process was shaped by contextual conditions including the characteristics of health services, the nature of hereditary breast and ovarian cancer risk-reduction decisions, gendered roles, and the women's perceived proximity to cancer. The women engaged in five decision-making styles, and these were characterized by the use of specific decision-making approaches. These findings provide theoretical insights that could inform the provision of decisional support to BRCA1/2 carriers.

Keywords

cancer, breast; cancer, genetics; cancer, ovarian; cancer, psychosocial aspects; cancer, screening and prevention; decision making; grounded theory; surgery

A woman who receives a positive test for a genetic mutation predisposing her to breast and ovarian cancer is presented with a myriad of risks and decisions. Those with a BRCA1 or BRCA2 (BRCA1/2) mutation have a lifetime risk of 45% to 88% for breast cancer and 11% to 65% for ovarian cancer (Antoniou et al., 2003; Evans et al., 2008; Ford et al., 1998). Hereditary breast and ovarian cancer (HBOC) risk-reducing (RR) options include early detection procedures such as breast self-examination, clinical breast examination, mammography, and magnetic resonance imaging. No proven effective screening exists for ovarian cancer. The most effective breast cancer prevention strategy is risk-reducing mastectomy (RRM), generally provided with the option of reconstructive surgery. Similarly, ovarian cancer is best prevented by risk-reducing salpingo-oophorectomy (RRO). Although

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it is recognized that making decisions about these RR options is complex and holds significant consequences, little is known about women's decision-making processes. Accordingly, our aim in this study was to develop a theory about women's experiences of making decisions about RR strategies following the disclosure of BRCA1/2 genetic test results. Understanding women's decision-making processes is an essential step toward developing clinical tools to support decision making.

Background Literature

Research investigating patients' decision making about cancer prevention (Bowen et al., 2006; Gorin, Wang, Raich, Bowen, & Hay, 2006; Myers, 2005; Wackerbarth, Peters, & Haist, 2008), breast cancer treatment (Balneaves & Long, 1999), and genetic testing (Burgess & d'Agincourt-Canning, 2001; d'Agincourt-Canning & Baird, 2006; Sherwin & Simpson, 1999) has provided insights into the complexity of these decisions and the importance of social influences on autonomous decision making. An increasing number of theorists have advocated for a relational view of autonomy that characterizes the decision maker as embedded in relational networks that include family, friends, and health professionals, as well as institutional, political, and social systems (Donchin, 2000; Sherwin, 1998). This stands in contrast to the individualistic, objective view of autonomy prevalent in early biomedical ethics literature and practice (Rodney, Burgess, McPherson, & Brown, 2004). Relational autonomy highlights the dynamic balance among people who are closely involved in each other's lives, with the individual dependent on close others when trying to achieve a goal (Gilbar & Gilbar, 2009). These relational networks are accompanied by social obligations, including roles and responsibilities, which provide the framework within which decisions are made (Sherwin).

Family influences have been well documented in cancer prevention and breast cancer treatment decision making (Gilbar & Gilbar, 2009; Hilton, 1994). Several studies have shown that an individual's family responsibilities influence her or his genetic testing decisions because she or he is aware of family interests in obtaining genetic information, as well as social obligations and personal interests in maintaining these relationships (Burgess & d'Agincourt-Canning, 2001; d'Agincourt-Canning, 2006; Etchegary et al., 2009; Hallowell, 2000; Hallowell et al., 2003; Mellon et al., 2009). In addition, the gendered context, which shapes the different roles, responsibilities, and activities ascribed to individuals according to their gender, has been shown to figure prominently in women's experiences of cancer prevention and treatment decisions (Helms, O'Hea, & Corso, 2008; Kearney, 2006; Lund-Nielsen, Muller, & Adamsen, 2005; Ogden & Lindridge, 2008), as well as genetic testing decisions (d'Agincourt-Canning & Baird, 2006). Despite the significance of family and gender, decision-making theories have largely failed to account for the influence of these and other social influences.

Researchers have begun to describe BRCA1/2 carriers' experiences and satisfaction with HBOC RR strategies (Josephson, Wickman, & Sandelin, 2000; Kenen, Shapiro, Hantsoo, Friedman, & Coyne, 2007; Lloyd et al., 2000; Metcalfe, Esplen, Goel, & Narod, 2004), yet few studies explain the preceding decision-making processes (McCullum, Bottorff, Kelly, Kieffer, & Balneaves, 2007). The limited existing research has largely been descriptive,

incorporating such theories of health behavior as the expected-utility theory (Unic, Verhoef, Stalmeier, & van Daal, 2000), or the self-regulation model of illness representations (Decruyenaere, Evers-Kiebooms, Welkenhuysen, Denayer, & Claes, 2000; Kash, Holland, Osborne, & Miller, 1995). These theories, however, do not address complex decision-making situations wherein multiple RR options need to be considered; nor do they take into consideration the other unique factors that influence women who are at risk for HBOC, such as family experiences of cancer (d'Agincourt-Canning, 2005; Hallowell, Jacobs, Richards, Mackay, & Gore, 2001; Mellon et al., 2009) and the associated heightened levels of perceived cancer risk, anxiety, and distress (Antill et al., 2006; Claes et al., 2005; Coyne, Benazon, Gaba, Calzone, & Weber, 2000; Coyne, Kruus, Racioppo, Calzone, & Armstrong, 2003; Fang et al., 2003; Fry, Rush, Busby-Earle, & Cull, 2001; Hallowell, 2000; Hurley, Miller, Costalas, Gillespie, & Daly, 2001; Kash et al., 2000; Meiser et al., 1999; Meiser et al., 2000; Stefanek, Enger, Benkendorf, Flamm Honig, & Lerman, 1999; Tiller et al., 2005; Trask et al., 2001; Unic et al., 2000; Wellisch & Lindberg, 2001). Also complicating these decisions are the unique risks associated with RR surgery on self-identity, body image, and femininity (Claes et al.; Fang et al.; Lodder et al., 2002; Matloff, Barnett, & Bober, 2009). Because of the complexity of RR decision making in the context of HBOC there has been a desire to develop decision support interventions. A better understanding of women's decision-making processes and the social contexts that influence these processes is needed to guide the development of supportive interventions.

Methods

We used a grounded theory approach (Charmaz, 2006; Strauss & Corbin, 1998) to gain an understanding of the HBOC RR decision-making processes of women with BRCA1/2 mutations. The hospital and university research ethics board approved all procedures.

Participants and Sampling Strategies

In this study, we included women with positive BRCA1/2 genetic test results who were older than 18 years of age and English speaking. We excluded women currently undergoing diagnostic testing or treatment for cancer, but we did not exclude women with a history of cancer because they, too, were making decisions regarding HBOC RR strategies rather than cancer treatment. This helped us to investigate how previous experiences of cancer, both personal and familial, influenced decision making. We recruited participants through a hereditary cancer program that provided the following recommendations to BRCA1/2 carriers: (a) for women between the ages of 30 and 69, clinical breast examination is recommended biannually, and magnetic resonance imaging and mammography are recommended annually; (b) no ovarian cancer screening is recommended; (c) RRM is not recommended, but rather is framed as a personal decision to be discussed with a health professional; and (d) RRO is recommended once childbearing is complete (Horsman et al., 2007). Hereditary cancer program staff, including nurses, genetic counselors, and physicians, gave potential participants a letter of invitation and we telephoned those women who mailed the completed consent-to-contact form to the research team.

We recruited women into this study from December, 2007 to August, 2008. We initially used open sampling and, following preliminary analysis, proceeded with theoretical sampling on the basis of relevant issues, concepts, and insights gained from initial data (Charmaz, 2006). We continued with data collection until no new theoretical insights emerged, categories were well developed, and relationships among categories were explained (Charmaz). This was achieved following interviews with 22 women. We assigned a pseudonym to each participating woman to maintain her anonymity.

Data Collection Procedures

The first author conducted in-depth interviews lasting 45 to 90 minutes following receipt of written informed consent from the women. We digitally recorded and transcribed verbatim all interviews. We began the initial interviews with open-ended questions to elicit participants' perspectives, per a preliminary interview guide designed to query phenomena involving processes (Charmaz, 2006). For example, we asked women to describe what first led them to consider RR surgery, how this decision changed over time, and how this decision was similar to and different from the way they made other types of decisions. As we proceeded with data collection and analysis, we changed the nature of the interview questions, with our questions becoming more specific to fill in gaps, explore important areas in greater depth, and verify emerging findings and relationships among concepts. This enabled us to advance theory development in successive interviews because we continuously verified the emerging theory with the participants. We also conducted follow-up interviews with 4 of the 22 women previously interviewed to clarify specific questions and invite their responses to preliminary findings. These women were selected because they represented variation in their decision-making experiences.

Data Analysis Procedures

We collected and analyzed the data simultaneously, constantly comparing the data from different participants, incidents, and categories, until we developed a substantive theory (Charmaz, 2006; Strauss & Corbin, 1998). We began data analysis by reading the interview transcripts line by line and highlighting passages that reflected important ideas and themes. We then condensed these open codes, sorted them into categories, and entered them into the qualitative data management software program NVivo (QSR International, 2002), after which we coded the interview transcripts. During the next phase of analysis, axial coding, we focused on creating, testing, and modifying linkages in the data, which we supplemented by memo writing and diagramming the developing categories and processes. We continued with this until we placed all emerging categories and subcategories in a theoretical framework and described the connections between categories (Charmaz). Finally, by refining the categories through selective coding, we identified a central concept under which all other categories were subsumed, thereby explaining most of the variation in the data. As an investigative team we thoroughly discussed emerging themes, categories, and concepts throughout the data-analysis process.

Rigor

The strength of the research process was supported by our systematic approach to data collection and analysis, our use of a data management computer software program, and the

range of expertise represented within the research team. Our ability to compare and contrast emerging themes and tailor questions in the subsequent interviews accordingly was enhanced because one author conducted the in-depth interviews. As a means of ensuring resonance, a criteria contributing to rigor (Charmaz, 2006), we shared preliminary findings with participants in succeeding interviews to obtain their comments on how the emerging theory fit with their decision-making experiences. Even though the theory was not an exact representation of each individual's experience, the participants were able to recognize themselves in the descriptions of decision making implied within the theory. We enhanced the credibility of this study by providing vivid descriptions of the findings, with references to representative quotations and experiences from the data.

Guiding Analytical Theories: Relational Autonomy and Gender

Our analysis of data was guided by theories of relational autonomy (Hartrick Doane & Varcoe, 2005; Sherwin, 1998) and gender (Butler, 1990; Connell & Messerschmidt, 2005; Johnson, Greaves, & Repta, 2007; Lyons, 2009; Saltonstall, 1993). Using a relational autonomy lens during data analysis helped us to contextualize women's experiences, and guided our exploration of the personal factors, interpersonal relationships, and wider social contexts within which they made decisions. For example, when coding the transcripts, we paid particular attention to the women's descriptions of how different people, including family members, friends, health providers, and other BRCA1/2 carriers, were involved throughout the decision-making processes. Gender, as a socially prescribed and experienced dimension of femaleness (and maleness; Connell & Messerschmidt; Johnson et al.; Lyons), was also used to analyze the data. Using gender as an analytical tool helped us explore the role of femininity in decision making in the context of HBOC, and the ways in which RR decision making threatened or enhanced self-identity as a woman. It also enabled us to examine the influence of gendered roles in relation to family, friends, and health professionals on HBOC RR decision making.

Sample Characteristics

The mean age of the 22 participants was 51 years (ranging from 28 to 80 years). The women were from diverse ethnic backgrounds, with the majority having some college or university education ($n = 15$) and being employed either full- or part time ($n = 18$). Most were married ($n = 17$), and more than half had children ($n = 12$). Five women had genetic testing in the previous year, 4 women had genetic testing in the previous 5 years, and 13 women had genetic testing more than 5 years prior to interview. Five women had a previous cancer history, none of whom were receiving cancer treatments.

Findings

The Process of Preserving the Self: HBOC RR Decision Making

Our findings from this study provide a theory of women's experiences of making decisions about HBOC RR strategies. In the following sections, we describe the overarching process of preserving the self, as well as the contexts influencing the women's HBOC RR decisions. We then outline the decision-making approaches the women used throughout the process of

preserving the self. Finally, we break this process down into five styles of decision making, describing each in turn (see Figure 1).

The overarching decision-making process related to HBOC RR strategies was directed toward preserving the self. Being at risk for HBOC and having to consider RR strategies threatened the women in four dimensions of self: their physical health, self-identity as a woman, relationships with others, and emotional well-being. As Christine, a single, middle-aged woman recalled, “It’s not rational but it [RRO recommendation] felt threatening, and it definitely felt like I was being threatened on some survival level.” Engaging in decision making about RR strategies enabled women to attend to their physical health, and to protect and secure their self-identities as women, particularly as this related to their youth, beauty, sexuality, body image, and femininity. Active involvement in decision making about RR strategies also supported women in managing and fulfilling their roles and responsibilities to family, friends, and health professionals, and helped them to cope with emotions that accompanied HBOC decision making, including anxiety, worry, fear, and uncertainty. Although these four dimensions of the self do not encompass all aspects of self, they represent the most salient themes expressed by the women. The four dimensions of the self were interconnected and their degree of significance shifted over time and across RR strategies.

Although the focus on preserving the self often began immediately following receipt of genetic test results, the women who already considered themselves to be at high risk for HBOC had entered into this process long before testing. Other cues for engaging in this process included receiving information and recommendations from health professionals, engaging in cancer-prevention or early-detection strategies, and experiencing personal life changes, such as having children. The process began with women imagining how the effects of cancer screening, RR surgery, or cancer itself would challenge their physical health, self-identities, relationships, and emotional well-being. When women were not ready for imagined changes or saw them as conflicting with their perceptions of self, they made decisions that reinforced their current self-identities, relationships, emotional well-being, and/or physical health. Christine recalled her initial thoughts when RR surgery was recommended to her at the age of 37:

The first time I went to see Dr. [name] she mentioned that the preventative measure would be to have the ovaries removed and to remove the breasts as well. And I just thought well, might as well make me a penis and call me Steve at that point. You’re going to remove my breasts and my ovaries? And I kind of thought, okay, well, we’ll talk about this later.

At other times, when women were able to accept imagined changes, they made decisions that enabled them to accommodate or prepare for expected alterations to their identity and physical, emotional, and relational self.

Preserving the self involved five decision-making styles: snap, intuitive, deliberative, deferred, and if–then. Each of these styles was characterized by a unique combination of seven decision-making approaches and differed in the amount of time devoted to decisions, who was involved, and the degree to which the decisions were revisited. The women

engaged in different styles of preserving the self, depending on which dimensions of self they privileged. Of importance, the dimensions of self that were privileged and the decision-making styles used by each participant changed over time, across RR strategies, and were influenced by the contexts within which these decisions were situated. We provide additional details of these five decision-making styles following descriptions of the contexts that shaped HBOC RR decision making and the decision-making approaches used by the women in this research. Preserving the self was the process of decision making for each of the RR strategies, cancer screening, RRM, and RRO, despite the marked differences in these strategies. This process resulted in all women deciding to have breast cancer screening, 13 of 19 women with ovaries (3 women previously had bilateral salpingo-oophorectomy to treat medical conditions) undergoing RRO, and 3 of the 22 women with breasts undergoing RRM.

Contexts Shaping HBOC RR Decision Making

The process of preserving the self was influenced by the contexts in which women made RR decisions. These included (a) the characteristics of health care service, (b) the nature of HBOC RR decisions, (c) gendered roles, and (d) the women's perceived proximity to cancer.

The characteristics of health care services—Although access to medical care was purportedly guaranteed through government-funded health care programs, the women's efforts to make decisions were influenced by their perceptions that the health care system was "stressed," financially stretched, and characterized by scarcity. As such, the women believed they needed to be self-reliant and proactive, persistently "pushing" for consultations and timely appointments to gain information and support for decisions that would help them protect their health. Although there was a sense of appreciation for the access they had to resource-intensive, specialized services, this access was not always guaranteed in a timely manner. For example, the inability to access breast reconstruction immediately following RRM influenced women's decisions about RRM. Moreover, some women lived in rural areas where costs of travel, taking time off from work, and family responsibilities needed to be considered.

The research culture within the hereditary cancer program also influenced the women's decisions. For many, deciding to be part of a program closely linked to research was a moral action. Women saw themselves as "doing their part," with potential future benefits to other women with BRCA1/2 mutations and future generations. Maureen, a woman who had genetic testing 5 years previously, exemplified this:

I'm in the system, that's the other thing. So I think because I go, I benefit other people because I am being followed, and they have years with me.... But more so, my being in the system potentially will help with the decision making for somebody down the road, which is why I think I continue to go [to the hereditary cancer program].

The nature of HBOC RR decisions—HBOC RR decisions were complex because they involved uncertainty, were often irreversible, and were situated in medical encounters in which a nondirective approach was the norm. In addition to the lack of available conclusive

scientific evidence to guide decisions, women found it challenging to interpret the probability of developing HBOC, as well as age-dependent patterns of both breast and ovarian cancer presentation. The lack of absolutes about when, or if, they would develop HBOC led to uncertainty about the right time to make decisions. The women hesitated because preventing the possibility of a future cancer was at odds with the more immediate personal, emotional, and relational consequences of making decisions in the here and now.

Decisions about HBOC RR were framed as “big decisions” when RR surgeries were considered because of their irreversibility and profound impact on the women’s sense of self. This magnified the pressure some women felt to make the “right” decision in a way that encompassed all possible facets of the decision. Leslie recalled her conversation with her physician:

She just said, “You know it is irreversible, so once you’ve made that decision, there’s no turning back, so, take your time, and weigh the pros and cons.” And there are just so many pros and cons and it’s huge. I mean it really is huge.

Although recommendations exist for screening and RRO for women with a BRCA1/2 mutation, with respect to other types of RR decisions (e.g., RRM) the women received little guidance beyond encouragement to reflect on their own needs and values. Some women, especially those who had previously undergone cancer treatment, expected health professionals to provide their opinions and make recommendations because this was the norm in previous interactions. Those women who wanted more direction or collaboration attempted to obtain health professionals’ opinions by asking about hypothetical situations (i.e., “If I were your daughter, what would you tell her to do?”), what they would do if in their situation, and what other high-risk women had chosen.

Gendered roles—The construction of HBOC RR decisions by hereditary cancer programs as a “woman’s issue” and, therefore, a “woman’s decision,” resulted in a few women taking on the decision-making process independently. For the majority of the women, RR decisions were influenced by important relationships in their lives. Some women recalled listening politely to unsolicited advice offered by family as a means of maintaining existing family dynamics and demonstrating respect. The women also involved family members in the RR decision-making process because they perceived that the state, capacity, and function of their bodies had implications for the lives of others. For example, when making RRO decisions, the women elicited their partner’s family planning desires. In addition, responsibility for making RR decisions was accompanied by the duty to provide, generate, and communicate information with the family in a sensitive and appropriate manner, especially with family members with a previous cancer diagnosis. The women also felt an obligation to prevent cancer or detect it early to ensure they would be able to provide care to family members in the future. At times, the needs of others were prioritized over women’s own needs, resulting in the postponement of HBOC RR decisions.

Proximity to cancer—The women’s perceived proximity to cancer was also an important contextual factor shaping the process of preserving the self by influencing the women’s perceived HBOC risk, their emotional reactions, and their sense of urgency to make decisions. The women who described cancer as “far away” had known no relatives with

cancer and had not provided care to affected family members. These women were surprised by positive BRCA1/2 test results but experienced few threats to the integrity of the self because of the belief that “not everyone who carries the gene will get cancer.” As a result, there was a lack of urgency in the way they approached decision making.

Other women described cancer as “very close.” They had known a close relative with cancer, witnessed the disease from a young age, and provided care to a suffering relative. Five of the women in this study had a personal cancer history and most were also acutely aware of the possibility of recurrence. The women who felt “very close” to cancer perceived themselves at high risk for HBOC prior to genetic testing and expected positive test results. These women had already begun the process of making HBOC RR decisions, and test results confirmed that cancer was an imminent threat to be dealt with swiftly. Between these two extremes, the women presented a continuum of perceived proximity to cancer informed by the closeness of their relationship to a stricken family member, the role they assumed in caring for relatives, and their age when family members experienced cancer. This translated into varying levels of anxiety regarding the likelihood of cancer, as well as variations in perceptions of threat to women’s sense of self.

Decision-Making Approaches

The process of preserving the self involved the women’s use of seven decision-making approaches (see Table 1) that protected their physical and emotional well-being, their relationships with others, and their self-identity.

Engaging with others—The women in this study used the decision-making approach of engaging with others to attend to all four dimensions of the self. The women obtained advice and medical information crucial for protecting their physical self. They relied on family, friends, and health professionals—not just for interpretations of the scientific evidence, but also for teasing out what aspects of the evidence were most relevant to them. Women also sought out other women who had undergone RRO, RRM, and breast reconstruction to learn about their experiences, in efforts to determine the best way to protect their self-identities as women while at the same time protect themselves from cancer. Discussions centered on the physical and psychological effects of RR surgery on feelings related to youth, beauty, sexuality, body image, and femininity.

Engagement with others also reflected women’s attention to their emotional well-being and their relationships. To ensure significant others were prepared to provide support and help make decisions, some women brought them into their decision making by having them come to appointments, and discussed with them the implications of surgery. When involving others as sounding boards, the women “checked in” as they talked through the complexities underpinning their decisions. Other women communicated only the most necessary details to the people in their lives who were “overwhelmed,” as a means of keeping them in the loop while simultaneously protecting them from fear, anxiety, and worry. Engaging with others came with risks for some women, particularly those who “shocked” others by seriously considering RR surgery, as exemplified by Angela:

But she [family member] actually thought that it [RRM] was a stupid decision, and I had a few reactions like that: “Oh that’s stupid. You’re being stupid. Why would you do that?” I’ve had to defend myself by saying, “Well why not [have RRM]? What are you keeping exactly [by not having RRM]? You’re keeping risky material [breast tissue].”

Because of the unpleasant reactions of others, some women avoided contact with unsupportive individuals and limited the information they shared.

Looking inward—Looking inward was a decision-making approach that involved reflecting on and clarifying how HBOC RR decisions would influence their self-identities as women. The women reflected on the multiple functions and meanings of their breasts and ovaries, as evident in Lauren’s description:

It’s [breast] part of my body. It fed my daughter, it’s part of me. I have a lot of fears and concerns with having the surgery. I know most of them are just silly or in my head. I think the biggest obstacle would be myself. Feeling that I’m not a woman, I’m not attractive. Will my husband still want me?

The women questioned their ability to adapt to the functional consequences of RRM, including not being able to breastfeed and loss of breast sensitivity and related pleasure, and the surgically induced menopause and infertility associated with RRO. In looking inward, women realized their breasts and ovaries held very personal meanings, the loss of which was envisioned by some as disfigurement; getting old early; and becoming a man, an “old hag or wicked witch.” Some women, however, were embarrassed about attaching significant meaning to their breasts or ovaries, questioning whether this was vain or petty in light of the threat of cancer. In contrast, other women concluded their breasts or ovaries were trivial to their womanhood. When offered a “breast lift” while consulting a surgeon about RRM, Maureen responded, “My self-esteem is not wrapped up with how perky my breasts are.”

Paying attention to emotions—The decision-making approach of paying attention to emotions was a principal means by which the women protected their emotional well-being. Emotional reactions to genetic test results and medical guidance occurred automatically, ranged from indifference to distress, and subsequently guided information processing and decision making. The women considered the effects of these emotional responses on their current and future lives. For example, Jane, a retired woman, explained:

Seeing what my sister went through [being diagnosed and treated for breast cancer] and not wanting to do that. I mean she was very good about the whole thing, but I’ve had two years of worry with her and I just can’t go there. I’ve just got to get this [RRM] done.

When emotional responses were overwhelming, some women disengaged from the decision-making process until they could reflect more clearly on those responses. For other women, worry and distress were cues to immediately engage in decision making as a means of keeping those emotions in check.

Relying on intuition—Intuition was an automatic, visceral, instinctual, “gut” reaction that many of the women attended to as they considered RR strategies. Although similar to paying attention to emotions in that cognitive reasoning was not overtly employed, relying on intuition involved what women described as an automatic knowing, understanding, or believing. When faced with RR decisions, the women honored their intuitive beliefs about whether or not they would develop HBOC and the best course of action to protect them physically from cancer.

Making sense of the numbers—This approach involved efforts to interpret the probabilities, percentages, and statistics provided by health professionals. This took considerable time and energy because women went over and over the information and sought additional information to help them understand what the numbers meant. The women tried to integrate the numerical information they were given into their preexisting perceptions of HBOC risk in a way that made sense, provided a sound basis for decision making, or gave them reassurance that the decisions they had already made were the right ones. Rose, a younger woman aware of her genetic test results for more than 5 years, exemplified this:

When I do look at ovarian cancer in the family tree it seems like it was all women who were in their seventies, eighties. So I don't see any statistics that make me think that my 20% is going to happen before that. So just believing in the fact that I'm doing what I can to stay healthy and that statistically it could happen earlier but my family evidence is that it shouldn't happen so early.... So things like that make me feel comfortable with not going in for surgery.

Weighing pros and cons—Weighing pros and cons was a decision-making strategy whereby the women attempted to fully comprehend the impact of decisions on their sense of self. The women were inclined to try to “balance the whole thing out,” weighing the advantages and disadvantages of a decision on all of the dimensions of the self. As Jane explained,

I definitely weigh pros and cons. And with the ovarian thing, there was nothing con. Even the risks of the surgery were minor compared to the risks involved with cancer. There was no way I was going to keep those things [ovaries] in my body.

Some women performed a cursory inventory of those dimensions of self they perceived to be most threatened, whereas for others, the process extended over years and involved continually incorporated new pros and cons into the equation as they became known. These women experienced a constant internal dialogue because they went back and forth over various options and consequences. For some, it seemed as if they were going in circles as they reviewed options, constantly losing the balance they thought they had already achieved.

Taking time—Taking time involved women slowing the decision-making process down to give them time to establish what and when decisions would be made, and ensure their sense of self was not unduly threatened by the decisions they faced. The women were confronted with making decisions about HBOC RR strategies when they were healthy, and in the

context of their busy lives. For some, this was “just not the right time,” as evident in comments made by Scarlet:

Then I phoned Dr. [name], and I said maybe I should go and at least get on the wait list for this breast stuff. So she did a referral, and low and behold, within a week I get this phone call that I can go and see this plastic surgeon. And I thought, what? I thought it was going to be a two-year wait list, which would give me enough time.

By taking time, the women fit these serious decisions into personal timelines that acknowledged their responsibilities to family members. Other women needed time to employ additional decision-making approaches that served their self-identities, emotional well-being, or physical health.

HBOC RR Decision-Making Styles

The seven decision-making approaches described above were combined in five distinct styles of decision making that served to preserve the women’s sense of self (see Table 2). These included the snap, intuitive, deliberative, deferred, and if–then decision-making styles. Table 3 lists the number of women who used the decision-making styles for HBOC screening, RRO, and RRM decisions. Of note, a number of the women used more than one decision-making style throughout the process of deciding about each of the RR strategies. The use of these decision-making styles was also influenced by the RR strategy under consideration, and the previously described contexts within which these decisions were situated.

The snap decision-making style—The snap decision-making style was the most commonly used by the women to make decisions about RR strategies. This style was used when the women perceived the best option for them as a “no brainer.” These decisions were made with confidence and a sense that women could not be dissuaded or drawn into considering other options—even when presented with new information. This style typically involved a short time frame, limited information, instant processing, and the involvement of few other people, because a detailed analysis of options was considered unnecessary, and the women did not revisit their decisions. For example, Iris, an older woman who previously had breast cancer, shared that on the offering of RRO, “I thought I’m healthy, I don’t need that. It was just an automatic, ‘No, I don’t think so.’” As evident in Iris’s comment, the women’s perceived closeness to cancer influenced the use of the snap decision-making style. When cancer was perceived to be “far away,” decisions were automatically dismissed or postponed. In contrast, when cancer was seen as being “very close,” snap decisions were used in response to the urgency these women felt to reduce their HBOC risk. Women who made snap decisions focused on informing their family of their decisions in ways that were sensitive to their family members’ needs and well-being. The women’s decisions were reinforced when family members were in agreement, but when there were disagreements the women attempted to defend their decisions while also maintaining these relationships. Because of the rapid nature of the snap decision-making style, the women relied on only one of the four decision-making approaches that were characteristic of this style and that helped preserve the dimensions of self most threatened.

The intuitive decision-making style—The intuitive decision-making style focused on “gut feelings.” Compared to the snap decision-making style, the women took their time in making intuitive decisions and relied heavily on their knowledge and beliefs. Intuition carried more weight than trying to gather information and advice or understand the risk numbers. This style, used by only 3 women, helped to preserve the dimensions of self perceived to be most threatened. In addition to relying on intuition, the women also used the decision-making approaches of looking inward and paying attention to emotions. These women held tightly to their beliefs about if or when they would develop HBOC, which were shaped by their perceived proximity to cancer, even in the face of contrary information. This allowed the women to maintain their identities and experience little emotional upheaval. Health professionals struggled with this style and questioned the credibility of such decisions, which resulted in them offering women unsolicited information and advice. In these instances, the women made efforts to maintain their relationships with health professionals despite disparate views about HBOC risk reduction.

The if-then decision-making style—This style of decision making was conditional, and the women worked through possible future decisions under various conditions to increase their comfort with their current decisions. The women identified hypothetical situations that would threaten their self-identities as women (e.g., if RRM was recommended and timely reconstruction was unavailable), their relationships (e.g., if family members required care and the women believed they had an obligation to remain cancer free), emotional well-being (e.g., if screening became too distressing), or physical health (e.g., if diagnosed with breast or ovarian cancer). This often occurred in the context of women’s relationships with others, as Gwen, an older woman working part time, shared:

If somebody like my husband got sick and needed me to look after him for a long time I wouldn’t want to risk getting cancer. And I think maybe if I got grandchildren I would want to see them. So I might consider it [RRM] then to reduce the risks.

Rather than make decisions based on uncertain probabilities of developing HBOC, this was a process of conceiving of situations that would pose significant enough threats to the self that the women would be compelled to make different decisions than they had previously. The decision-making approaches used in this style were all directed toward anticipated future threats to the self.

The deliberative decision-making style—The deliberative decision-making style was an iterative technique that occurred over a number of months or years, wherein the women deliberated repeatedly about the RR decisions that confronted them. Owing to the irreversible nature of RRM and RRO and the profound impact on women’s lives, some women considered the deliberative style the most reasonable because it allowed them to consider all possible facets of the decision. The women made tentative decisions and then contrasted them by imagining different HBOC RR decisions and incorporating old and new information, advice, values, and beliefs. Deeply valued were the opinions of close family members who the women anticipated would be affected by these decisions. In the deliberative style, the women attended to all of the threats that RR strategies posed to each

of the four dimensions of the self. This complicated and prolonged the decision-making process because when the women privileged one aspect of the self, a different aspect of the self was sometimes threatened. Attending to all four dimensions of the self was only possible through the use of numerous decision-making approaches, as exemplified by Coral, a woman with a history of breast cancer:

I did go on the Internet and read, get some literature and books, talk to the doctors. I mean, the doctors are great.... I think I made the right decision and I think I made that decision based on what I think I know. Do you know what I mean? What I've read, what I think I know about myself, what I think I know about the statistics, what I know about just wanting to forget about things maybe and just say this is it, the last bit—I'm over and done and just carry on.

Moreover, because contexts changed over time (i.e., the women's status related to relationships, childbearing, and employment, and beliefs about their proximity to HBOC), the dimension of self most threatened by HBOC RR decisions also changed.

The deferred decision-making style—This style involved intentionally “putting off” HBOC RR decisions until a later, unspecified, and “right” time. The women used this style without hesitation, judging RR decisions to be premature and suitably pushed into the future, although not put off indefinitely. Angela, who considered cancer to be her “genetic destiny,” described her reactions to being offered RRO:

Gee, that's really scary. Let's just talk about that [RRO] when it becomes more of an issue. I have a lot of time still, and everything will change within that time, and it's just something for me to process within this period.

Putting RR decisions on the “back burner” was perceived as the best technique because the women saw no advantages to making immediate decisions and, by waiting, alternate options might become available. This style enabled them to carry on with their busy lives, attend to more pressing matters, cope with overwhelming emotions, or continue to reflect on the decisions they faced over extended time periods. Concentrating on familial responsibilities, including providing care to children and ailing parents, was considered more of a priority for the time being and was reinforced by the perception that HBOC was “far away.” Women who used the deferred decision-making style were more concerned about their self-identities, relationships, and emotional well-being than they were about the immediate physical threat of cancer. Accordingly, the decision-making approaches used in this style included taking time, looking inward, and paying attention to emotions.

Discussion

The results of this study shed new light on the process of decision making about HBOC screening, RRM, and RRO. We described a theoretical model that focuses on preserving the self. In this model, we conceptualized engaging in decision making as a way for women to attend to their physical health and protect themselves from cancer, as well as protect their self-identity as a woman, their emotional well-being, and their relationships. As a means of protecting these four aspects of the self, seven different decision-making approaches were used, which were reflected in five distinct decision-making styles. Over time, women used

more than one decision-making style when deciding about each of the RR strategies. The findings also indicate that the process of preserving the self was influenced by four main contexts: the characteristics of health services, the nature of HBOC RR decisions, gendered roles, and the women's perceived proximity to cancer.

The overarching aim of the preserving-the-self theory, with regard to protecting women's four main dimensions of the self, is supported by self-schema theory. Used by Esplen and colleagues (2009) to explain the changes experienced by BRCA1/2 carriers in their perceptions of themselves, self-schemas are mental representations of the self that might shift over time based on a woman's conception of who she is in the present, as well as memories of who she was in the past, plus visions of who she might be in the future. These future-oriented ideas of the self, referred to as "possible selves," are versions of the self one expects (e.g., healthy), fears (e.g., a victim of cancer), or wishes to be (e.g., a mother; Markus & Nurius, 1986). The women in this study appeared to experience challenges to their current self-schema when making decisions about HBOC RR strategies. Furthermore, some women struggled to hold on to their current self-schema while imagining a future self-schema.

Two noteworthy aspects of the women's self-schema that were threatened by HBOC RR decisions centered on womanhood and relationships with family. Although threats to the self-as-a-woman and the self-in-relation-to-others schemas are evident in research investigating genetic testing decisions (Etchegary et al., 2009; Hallowell, 1998), to our knowledge this study is the first to describe how these threats influence decisions about RR strategies. Many of the women in this study felt their self-as-a-woman schema was threatened because RR surgery had the potential to disrupt the function and meaning they attached to their breasts and ovaries. The women's self-in-relation-to-others schema encompassed the women's relational networks, which included their roles and responsibilities to others as mothers, wives, partners, sisters, and daughters. This self-schema was also threatened because RR strategies were envisioned as potentially disruptive to the women's relational networks by interfering with their abilities to fulfill their roles and responsibilities to others. When considering RR strategies, the women reflected on their willingness, readiness, or ability to face these challenges presently and in the future. At times, the women resisted shifts to their self-schema by engaging in decision making that reinforced their current perceptions of themselves (e.g., a woman with two breasts). At other times, the decision-making process facilitated becoming a future self (e.g., a woman protecting her children by reducing her risk through surgery). In other words, accommodating shifts in self-schema, particularly related to womanhood and relationships with others, was an integral part of the decision-making process.

The preserving-the-self theory complements health behavior theories that acknowledge the importance of context for health behavior, including the preventive health model (Myers, 2005), the social cognitive theory (Bandura, 1986), and the theory of stress, appraisal, and coping (Lazarus & Folkman, 1984). The theory of preserving the self extends these explanations by describing the social and personal contexts salient to decision making about HBOC RR. This theory also illustrates how women actively interpret and engage with these personal, social, and structural contexts and the inherent relational networks, which in turn

raises some important questions worthy of research. For example, understanding the specific decision-making needs of women living in remote communities related to HBOC RR strategies might provide insights that will extend the preserving-the-self theory and inform future decision-support interventions.

Study findings suggest that the decision-making process was complicated for some women because of the nature of consultations with health professionals who took a nondirective approach to offering RR options, a philosophy of care common in genetic counseling (Sharpe & Carter, 2006). Of note, some researchers consider this nondirective approach inadequate, and have advocated for shared decision making wherein health care providers make recommendations while the patient retains a crucial role in making the final decision (Elwyn, Gray, & Clarke, 2000; Smets, van Zwieten, & Michie, 2007). Shared decision making can complement a nondirective approach by providing guidance to health care professionals about how to engage patients in determining or negotiating the degree of desired directiveness (Elwyn et al.). Shared decision making has been strongly supported in cancer care (Stacey, Samant, & Bennett, 2008), and deserves additional investigation as a model for decision making about HBOC risk management.

The theory of preserving the self also highlights how women make decisions in the context of their gendered roles within their families. Although many family members provided practical, informational, and emotional support to women in making their decisions, other family members complicated the decision-making process by negatively reacting to women's RR decisions. Similar to other research involving women (Smith-DiJulio, Windsor, & Anderson, 2010) and BRCA1/2 carriers (Etchegary et al., 2009; Hallowell, 1998), some of the women in this study also attempted to balance the needs of others with their own needs and, occasionally, the needs of others constrained their decision making. These findings are consistent with theories such as the preventive health model (Myers, 2005), in which the social support and influence of significant others are considered to be central to decision making. These findings are also congruent with the theory of stress, appraisal, and coping (Lazarus & Folkman, 1984), wherein positive and negative support is considered to be the result of social systems that create resources and demands on individuals. The preserving-the-self theory extends these theories by illustrating how the family context created resources and demands for using particular RR decision-making approaches and ultimately shaped the decision-making process. These resources and demands were in part the product of gendered roles and responsibilities that the women in this study felt compelled to fulfill. This is consistent with the ideas of Hartrick Doane and Varcoe (2005), that gendered roles and inequities are played out in families in ways that are consistent with the wider fabric of society. Accordingly, "gendered family roles and experiences are not merely 'choices' made by individuals, but rather are enactments of wider social values, expectations, and ideologies" (Hartrick Doane & Varcoe, 2005, p. 67). Furthermore, through the illustration of how the family context created resources and demands that ultimately shaped the HBOC RR decision-making process, this study enriches the concept of relational autonomy by furnishing fine-grained details about how it operates in practice. Future research examining how diverse social and cultural contexts shape gendered family roles and how these, in turn, influence women's HBOC RR decisions will be an important next step. Such research could also contribute significantly to ongoing empirical and theoretical work

exploring how ethical concepts such as autonomy and consent are operationalized in cancer care.

The theory of preserving the self included both cognitive and emotional approaches of decision making that were heavily influenced by the women's perceived proximity to cancer, which appears to be akin to the concept of perceived risk. In other research, a woman's perceived cancer risk has been well established as a factor influencing the uptake of, preference for, or intention to seek RRM and RRO (Antill et al., 2006; Claes et al., 2005; Fang et al., 2003; Fry et al., 2001; Hallowell, 1998, 2000; Hallowell et al., 2001; Meiser et al., 1999; Stefanek et al., 1999; Stefanek, Helzlsouer, Wilcox, & Houn, 1995; Tiller et al., 2005; Unic et al., 2000; van Dijk et al., 2003; van Dijk, van Roosmalen, Otten, & Stalmeier, 2008).

Specific cognitive approaches, such as making sense of the numbers and weighing the pros and cons, as well as the central role of emotions in decision making and information processing, have been supported by existing theories (Balneaves & Long, 1999; Lazarus & Folkman, 1984; Leventhal, Brissette, & Leventhal, 2003; Miller, Shoda, & Hurley, 1996; Myers, 2005; Reyna, 2008). For example, in the cognitive-social health information processing model (Miller et al.) women's decisions about RRO are determined by how they cognitively and emotionally process information about their cancer risk. For many of the women in this study, distress and worry were long-standing emotions because of personal experiences of a cancer diagnosis and treatments, having witnessed family members with cancer, or caring for affected relatives. Similar to other research (d'Agincourt-Canning, 2005), this experiential knowledge, both empathetic and embodied, ultimately shaped how decisions were made. For example, the women used the decision-making approaches of paying attention to the emotions that accompanied being at risk for HBOC and taking the time needed to protect one's emotional well-being. The women's emotional well-being functioned as a motivator to both engage and disengage from decision making. It must be noted that RR decision making was so overwhelming for some that their decisions were predominantly directed toward coping with these emotions more than preventing or detecting cancer.

The cognitive and emotional processes used in the theory of preserving the self often functioned interactively, in parallel, and to varying degrees in the different decision-making styles. These findings lend support to the dual-process theories of information processing, wherein decisions involve the interaction of two overlapping systems of reasoning (Gilovich, Griffin, & Kahneman, 2002). One is deliberative and analytical, whereas the other is intuitive, automatic, nonreflective, associative, and experiential. The experiential system involves the use of heuristics—logical shortcuts that people use when processing information (Kahneman & Tversky, 1982). One main heuristic used in the experiential system is the affect heuristic, wherein positive or negative feelings are experienced consciously or unconsciously (Slovic, Peters, Finucane, & Macgregor, 2005). Although subsumed under the experiential category, in the theory of preserving the self the decision-making approaches of paying attention to emotions and relying on intuition were distinct. Relying on intuition, one's "gut" reaction, has also been used by women seeking genetic testing (d'Agincourt-Canning, 2006) and by individuals making other medical decisions

(Lam, Fielding, Chan, Chow, & Or, 2005; Reyna, 2008). The distinction between emotion and intuition in the preserving-the-self theory might be a reflection of different forms or expressions of the affect heuristic. Alternatively, intuitive decision making might be informed by emotions but also incorporate an automatic knowing, understanding, or believing based on previous experiences, values, or beliefs. Analyses of heuristic reasoning have shed light on patient delays in seeking evaluation of breast cancer symptoms (Facione & Facione, 2006), as well as women's perceived risk for breast cancer (Facione, 2002; Katapodi, Facione, Humphreys, & Dodd, 2005), and could guide a fine-grained analysis of decision making about HBOC RR that would complement the theory of preserving the self.

Study Limitations

Although this study offers the first (to our knowledge) theory describing BRCA1/2 carrier women's decision-making processes about HBOC RR strategies, several limitations must be noted. First, we recruited all of the participants through one provincial Canadian cancer program, and the experiences of women likely differ nationally and internationally because of variations in the provision of genetic services. There is much variability in the recommendations and options made available to BRCA1/2 carriers, and international differences in the rates of RRM uptake have been noted (Metcalf et al., 2008). Moreover, we did not access any participants with positive BRCA1/2 results who chose not to partake in HBOC screening. It is possible that the participants represent a homogeneous group with ready access to services and beliefs in conventional cancer prevention and early detection. Because we restricted the sample to women who were not undergoing diagnostic testing or treatment for breast cancer, it precludes the application of the theory to women with cancer and faced with cancer treatment decisions. Furthermore, although insights from this study might spark ideas for how individuals make health decisions following other types of genetic tests, such as genetic testing for colorectal cancer, additional research is required to understand these specific contexts.

Study Implications

The theory of preserving the self provides direction for the provision of HBOC RR decision support. Foremost, because women's decisions go beyond their physical health, which is generally the focus of health professionals, decision support should include attention to a woman's self-identity, her emotional well-being, and her relationships with others. For example, strategies to help women reflect on their beliefs about the effects of RR options on their femininity, body image, and sexuality at a time that is right for them, and in a manner that takes into account the potential emotional consequences, might be helpful. As well, based on the findings, educational, information-based approaches are less likely to be successful than those incorporating psychosocial interventions aimed at emotional coping and adjustment. Making available different avenues by which women can obtain information and social support, such as online or in-person support groups or networking forums, might be valuable to women who learn from the first-hand experiences of others. Finally, incorporating a relational framework that focuses on women's relational networks along with their roles and responsibilities would be suitable considering the complexities of HBOC RR decision making. Future research might examine the benefits of these approaches in

supporting HBOC RR decision making. Moreover, the preserving-the-self theory will require testing in a larger sample, perhaps through quantitative means, to confirm or revise the theory.

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Figure 1.
Preserving the self through hereditary breast and ovarian cancer risk-reducing decisions

Table 1**Descriptions and Examples of Decision-Making Approaches**

Decision-Making Approach	Description and Example
Engaging with others	Receiving medical guidance, involving, checking-in with and protecting family members, and learning from the first-hand experiences of others: “My mom could talk it through [risk-reducing oophorectomy decision], and my sister could listen and talk it through, and my girlfriends could do that, but not him [husband]. I would tell him more what I thought I was going to do.”
Looking inward	Introspective reflection in which women considered and clarified aspects of self-identity that could be threatened by hereditary breast and ovarian cancer risk-reducing (RR) decisions: “I mean you can fill the clothes with pads and stuff like that, but I don’t know, I think that [risk-reducing mastectomy] would really change how I felt about my femininity.”
Paying attention to emotions	Taking note of, discerning, and monitoring emotions; considering the effects of RR decisions on emotions, followed by tending to these emotions: “I just made the decision [to have risk-reducing oophorectomy] because I thought that that was my best opportunity to not worry, and the CA125 [a screening test for a serum biomarker for cancer] was not reliable, and even though I was having that, I didn’t really even think it was worth having.”
Relying on intuition	Acknowledging, trusting, and following initial “gut” reactions and beliefs: “I don’t remember ever swaying far from my gut feeling, you know, considering, I think I’ve basically stuck with my gut feeling.”
Making sense of the numbers	Interpreting and personalizing probabilities, percentages, and statistics about the risks of developing cancer and the efficacy of RR strategies to detect cancer early or prevent cancer: “I mean you’re sort of looking at all the statistics. You know, this gene has this percent and that gene has that percent, and evidently having both one and two doesn’t increase my risk.”
Weighing pros and cons	Weighing and balancing the positives, benefits, and advantages of RR decisions with the negatives, risks, and disadvantages of RR decisions: “I have actually spent a few moments trying to weigh out the pros of breast feeding versus, you know, the percentage of risk that might occur over the next few years while we’re waiting to have the next kid.”
Taking time	Fitting RR decisions into personal timelines by putting the decisions on hold until a more appropriate or desirable time, or until decisions could be made with full knowledge and consideration of benefits and risks: “You’re going to remove my breasts and my ovaries, and I kind of thought, okay, well we’ll talk about this later, when I’m ready.”

Table 2

Decision-Making Styles Characterized by Decision-Making Approaches

Decision-Making Styles	Privileged Dimensions of Preserving the Self	Use of Decision-Making Approaches					Weighing the Pros and Cons
		Looking Inward	Paying Attention to Emotions	Taking Time	Relying on Intuition	Engaging With Others	
Snap*	Dimension of self that was initially most threatened	X	X			X	X
Intuitive	Dimension of self that was intuitively most threatened	X	X		X		
If-Then	Dimension of self that was hypothetically most threatened	X	X	X	X		X
Deliberative	Physical health, self-identity, relationships and emotional well-being	X	X	X		X	X
Deferred	Self-identity, relationships and emotional well-being	X	X	X			

*The women used only one of the four possible decision-making approaches when making a snap decision.

Table 3

Participants' Use of Decision-Making Styles for Risk-Reducing Strategies

Decision-Making Style	Risk-Reducing Strategy		
	Screening	Risk-Reducing Oophorectomy	Risk-Reducing Mastectomy
Snap	18	9	4
Intuitive	3	2	1
If-Then	0	0	10
Deliberative	1	12	9
Deferred	2	5	10