

# Decision-Making Process of Women Carrying a *BRCA1* or *BRCA2* Mutation Who Have Chosen Prophylactic Mastectomy

Megan McQuirter, MSc(A), Luisa Luciani Castiglia, BScN, CON(C),  
Carmen G. Loiselle, N, PhD, and Nora Wong, MS

Germline mutations in the *BRCA1* or *BRCA2* genes are responsible for most hereditary breast cancers (National Cancer Institute, 2008). Carriers are more likely to develop breast cancer and at a younger age than the general population (Rogozinska-Szczepka et al., 2004). A meta-analysis by Chen and Parmigiani (2007) reported that the risk for developing breast cancer in mutation carriers aged 70 years or younger varies from 40%–70%.

Women with *BRCA1* and *BRCA2* mutations face a number of options to manage their breast cancer risk, including increased surveillance, chemoprevention, prophylactic salpingo-oophorectomy, and prophylactic mastectomy (Zakaria & Degnim, 2007). Prophylactic mastectomy dramatically reduces breast cancer risk for mutation carriers by 90%–95% (Rebbeck et al., 2004; van Sprundel et al., 2005); however, the uptake of prophylactic mastectomy varies from 0%–49% in Austria, Canada, France, Israel, Italy, Norway, Poland, and the United States (Metcalf, Lubinski, et al., 2008). The potential for surgical complications and aesthetic concerns have been suggested as deterrents (Ray, Loescher, & Brewer, 2005; Zakaria & Degnim, 2007). In addition, some women may be opposed to prophylactic mastectomy, feeling that the loss of a body part mimics having breast cancer (Press et al., 2005). Women at high risk for breast cancer face the challenge of deciding whether to undergo surgery for risk reduction, to rely on the less effective but less aggressive option of chemoprevention, or to be screened frequently for early detection (Kurian et al., 2005). As a result, the current study sought to better understand the decision-making process of women carrying a *BRCA1* or *BRCA2* mutation who have chosen prophylactic mastectomy.

## Literature Review

Decision making about breast cancer has been the subject of research in various contexts. Several studies have explored the experience of women newly diagnosed

**Purpose/Objectives:** To explore the decision-making process of women with a *BRCA1* or *BRCA2* gene mutation who have chosen to undergo prophylactic mastectomy.

**Design:** Cross-sectional, qualitative, descriptive design.

**Setting:** Participants were recruited from an outpatient cancer prevention center in the oncology and medical genetics departments of a large university-affiliated hospital in Montreal, Quebec, Canada.

**Sample:** 10 women carrying a *BRCA1* or *BRCA2* mutation; 8 previously had had a prophylactic mastectomy and 2 were scheduled for surgery at the time of study.

**Methods:** Semistructured, in-depth interviews were conducted. Field notes were written and audiotapes were transcribed verbatim. The textual data were coded and analyzed.

**Main Research Variables:** Decision-making process for prophylactic mastectomy.

**Findings:** Two broad findings emerged. First, several intrapersonal and contextual factors interacted throughout the process to move women either closer to choosing a prophylactic mastectomy or further from the decision. Second, all women reported experiencing a “pivotal point,” an emotionally charged event when the decision to have a prophylactic mastectomy became definitive. Pivotal points for patients included either receiving a positive result for a genetic mutation or a breast cancer diagnosis for herself or a family member in the context of positive mutation status.

**Conclusions:** Decision making about prophylactic mastectomy was an affective and intuitive process incorporating contexts and their relations rather than a rational, straightforward process of weighing pros and cons.

**Implications for Nursing:** Supportive interventions for women in this population should explicitly address the individual and the inter-relationships of contextual factors that shape decision making about prophylactic mastectomy while recognizing important affective components involved.

with breast cancer who were making surgical treatment decisions. Preference for involvement in decision making varied from active participation to deferring to the expertise of physicians (Hack, Degner, Watson, & Sinha, 2006;

Janz et al., 2004; Kenny, Quine, Shiell, & Cameron, 1999; Lacey, 2002). In genetic testing, subjective, perceived risk was most strongly related to the actual decision to pursue testing (Bleiker, Hahn, & Aaronson, 2003).

Knowledge of women's decision-making style and reasons associated with having a genetic test can add to the understanding of prophylactic mastectomy in mutation carriers. However, the inherent uncertainty of actually developing cancer and the lack of a guarantee for a cancer-free future, even with preventive surgery, distinguishes this decision-making process from others. Issues of ambiguity and uncertainty regarding the outcomes of risk-reduction measures as well as difficulty in interpreting probabilistic information must be considered (Vadaparampil, Wey, & Kinney, 2004), particularly in prevention when more than one reasonable course of action can be taken.

Literature examining aspects of prophylactic mastectomy is incomplete. Several studies reported on women's hypothetical interest in prophylactic mastectomy prior to testing and found it to be an unpopular option (Eisinger, Julian-Reynier, Stoppa-Lyonnet, Lasset, & Nogues, 2000; Meiser et al., 2000, 2003; Press et al., 2005; Stefanek, Enger, Benkendorf, Honig, & Lerman, 1999). In a study of 246 women, about 45% could not imagine having a prophylactic mastectomy because of its radical nature (Press et al., 2005). However, the participants were untested and did not face the same real-life decision-making process as women who have tested positive for the *BRCA1* or *BRCA2* gene mutation.

Choosing prophylactic mastectomy has been linked to having a family history of breast cancer (Metcalf, Foulkes, et al., 2008), a personal history of breast cancer (van Roosmalen et al., 2004a), a physician recommendation (Schwartz et al., 2004), and young children (Lodder et al., 2002; Unic, Verhoef, Stalmeier, & van Daal, 2000). In addition, van Dijk, van Roosmalen, Otten, and Stalmeier (2008) found that the decision was correlated most strongly to a woman's anticipated feelings of regret if she was to get breast cancer. Higher levels of distress or perceived risk for developing breast cancer have been associated with a higher probability of undergoing preventive surgery (Bebbington Hatcher & Fallowfield, 2003; De Leeuw, van Vliet, & Ausems, 2008; Hallowell, 1998; Lodder et al., 2002; Stefanek, Helzlsouer, Wilcox, & Houn, 1995; van Dijk et al., 2003). Although the findings are insightful, the studies provide a limited explanation of relationships among factors leading to the decision.

A series of studies documented the role of decision-making interventions in helping women choose their best treatment option. They varied from responses to an information booklet (McCullum, Bottorff, Kelly, Kieffer, & Balneaves, 2007) to more sophisticated decision aids that incorporate values clarification and probability outcomes (Metcalf et al., 2007; van Roosmalen et al., 2004b), with one using an interactive CD (Schwartz et al., 2009).

However, developing and testing interventions without a prior understanding of the process of decision making may be premature.

Qualitative studies of women's experiences with prophylactic mastectomy have explored the nature of information perceived as helpful for decision making (Ray et al., 2005; Rolnick et al., 2007). Women's surgical experiences and psychosocial outcomes also have been described (Bebbington Hatcher & Fallowfield, 2003; Lloyd et al., 2000). However, the decision-making processes leading to choosing prophylactic mastectomy were not the focus of these studies.

The literature review revealed that little is known about how women choose to have a prophylactic mastectomy. Therefore, the current study aimed to explore the decision-making process of women carrying a *BRCA1* or *BRCA2* mutation who have had or plan to have a prophylactic mastectomy.

## Methods

A qualitative design (Sandelowski, 2000) was used to generate an in-depth description of the decision-making process in a small sample of women carrying a *BRCA1* or *BRCA2* mutation who chose prophylactic mastectomy. Participants were recruited from a large university-affiliated hospital. Inclusion criteria were being a woman, testing positive for a *BRCA1* or *BRCA2* mutation, being able to communicate in English or French, being aged 18 years or older, and having made the decision to have a prophylactic mastectomy.

Following institutional ethical approval, 12 women were approached by a genetics counselor to participate in

### Introductory Statements

- We are conducting a study about how women who are carriers of the *BRCA1* or *BRCA2* gene mutation decide to have a prophylactic mastectomy. We would like to hear about this from the perspective of women who have actually undergone this experience. We are interested in hearing your story.

### Semistructured Interview Questions

- Can you describe the journey that you went through in deciding to have a prophylactic mastectomy?
- Please tell me about the options that were offered to you, what you thought about them, and how you felt about them.
- In reviewing these options, what did you consider as important in terms of making a decision?
- Can you describe what factor(s) had the biggest effect on you choosing to have a prophylactic mastectomy?
- Did other people have a role in this decision? If so, could you describe who they are and how they were involved?
- In reviewing how you arrived at this decision, can you tell me if your decision changed over time? If so, can you describe how?
- In general, what would you say was the most helpful in this process? The least helpful?
- Would you like to add anything else that you feel is important but has not been discussed yet?

### Figure 1. Prophylactic Mastectomy Interview Guide

the study. All agreed to participate, but two were unable to be interviewed because of scheduling conflicts, leaving a convenience sample of 10 women. A small sample size was used because this area has not been investigated previously. Eight interviews were conducted at the hospital, and two were done at participants' homes. Written informed consent was obtained. Semistructured interviews with open-ended questions were used to provide structure and focus on topics related to the decision-making process (Morse & Field, 1995). A sample list of interview questions is provided in Figure 1. Interviews were audio-taped and transcribed verbatim. In addition, detailed field notes were written immediately after interviews to document nonverbal information and impressions (Morse & Field, 1995). Sociodemographic and medical information also was obtained.

Rigor was enhanced by addressing issues of credibility, transferability, and confirmability (Carnevale, 2002). Credibility was improved by triangulation of data sources (transcripts and field notes) and investigators (Carnevale, 2002). Transferability was addressed by using thick description, and keeping an audit trail helped enhance the study's confirmability (Loiselle, Profetto-McGrath, Polit, & Beck, 2007).

Data were analyzed with the method of thematic content analysis (Burnard, 1991), adapted from grounded theory. Analysis began during the data collection period and continued throughout the study. Audiotapes were transcribed verbatim and coded line by line. Data were initially broken down into parts and subsequently conceptualized into categories, with the outcome being a description of factors involved in decision making. A secondary analysis examined participants' decision-making trajectories over time.

## Results

Demographic data are summarized in Table 1. Participants followed diverse decision-making trajectories in choosing prophylactic mastectomy. However, similarities also were noted. Women seemed to be influenced by factors from their past (echoes from the past) and present (the here and now) as well as by thoughts about the future. The elements interacted to provide added meaning to present experience. Along a given timeline, the decision-making process involved a complex interplay among intrapersonal factors, originating within the women, and contextual factors, arising externally from their environment. Personal cancer experience, the preference to be involved in decision making, desire for support, and body-image concerns are examples of personal factors. Contextual factors included prior cancer experiences in the family, physician recommendation, and available support. Notably, the overlay or "fit" between the woman (personal) and her circumstances (contextual factors), not just the factors themselves, influenced the decision

**Table 1. Sample Characteristics**

Characteristic	$\bar{x}$	Range
Age (years)	45.8	29–59
Time since mastectomy (years)	6.5	2–10
Characteristic	n	
<b>Marital status</b>		
Married or partnered	9	
Single	1	
<b>Have children</b>		
Yes	9	
No	1	
<b>Mastectomy</b>		
Postmastectomy at time of interview	8	
Awaiting surgery at time of interview	2	
<b>Personal history of breast cancer</b>		
Yes	6	
No	4	
<b>Family history of breast cancer</b>		
Yes	9	
No	1	
<b>Time since knowledge of mutation status to mastectomy decision (years)</b>		
With no personal history of breast cancer		
• Less than 1	2	
• 1–4	2	
With personal history of breast cancer		
• Less than 1	4	
• 1–3	2	
N = 10		

whether or not to have prophylactic mastectomy. For example, a woman's personal goals in the context of her career and family planning were significant themes.

For all participants, a specific experience acted as a pivotal point that made the decision to have prophylactic mastectomy more definitive. For five participants, the event was obtaining the knowledge of being positive for a *BRCA1* or *BRCA2* mutation, with or without a previous breast cancer diagnosis. For the other five, a subsequent breast cancer diagnosis in themselves or a family member with the awareness of her mutation status resulted in the decision to have a prophylactic mastectomy.

## Interacting Factors Along a Timeline

**Echoes from the past:** Because of the genetic component of their risk, most participants had relatives affected by breast or ovarian cancer, which had a profound impact on the women. They expressed fears of getting cancer or dying from it. A woman's current experience also was affected by her personal history of breast cancer. One woman said,

You always hope that it's not going to be me, I'm not going to be a carrier, okay, I'm a carrier, oh, I'm not going to get it, yet I've lived with the fear of getting it. . . . It was present all my life, you can't, you can't avoid it.



**The here and now:** In this period, women actively made their decisions regarding mastectomy. During this time, rich interactions between intrapersonal and contextual factors took place. Knowledge of having a positive mutation status or being diagnosed with breast cancer evoked fear and painful memories. In talking about her own cancer diagnosis, one woman said, "It was too much of a shock for me. To be in the same situation, you know, [as my mother]. Cancer, me, what now? . . . That's *all* I kept saying." With regard to her cancer recurrence, she said, "So I didn't want to *be* like that. I didn't want to go through that. I think that's what was . . . inside my own head when it came back." After testing positive for a mutation, another participant said, "My sister had a lot of trouble with chem[otherapy], so knowing what she went through . . . I don't want to go through that." Some poignantly related their age at diagnosis to that of their mother's diagnosis or death. "When I reached the age that [my mother] was diagnosed, that was a big milestone in my life. . . . At that age I thought, 'Phew,' then I was diagnosed the next year."

A recurrence or a mutation-positive test result evoked past distress for women who had had breast cancer previously. Some discussed the "anguish of having to wait for the result [of diagnostic tests]." One woman talked about how "stereotactic biopsies were excruciating." Another described how difficult chemotherapy had been. "It was *rough*. . . . I was sick, the headaches that I've had . . . I couldn't work. I couldn't function." Many talked about "not wanting to go through that again." Therefore, having breast cancer or being a mutation carrier must be viewed in the context of a family or personal history of breast cancer.

The extent to which physician recommendation played a role in a woman's decision depended on her information-seeking style and preference for involvement in decision making. Some women had implicit trust in the doctor and followed his or her advice. One said, "Maybe I'm very traditional, but I trusted the MD. . . . [The recommendation] was a big motivating factor." Another woman said having a panel of physicians recommend the surgery was helpful. "You know, if I were to get . . . 10 different opinions, 5 said yes and 5 said no, now I would be torn." Another expressed frustration that she had to seek information and advocate for herself regarding gene testing and prophylactic mastectomy, which she felt should have been her doctor's role. "It was always me who had to push. . . . I was never given information about all this. . . . That was frustrating." Reflecting a very active information-seeking style, one participant explained, "I started doing some research about prophylactic mastectomy and the risk reduction. When I brought [it] home, and read them sometimes with my husband, we said [prophylactic mastectomy] makes complete sense." For her, advice from her physician was less important than her own research.

Family support interacted with the women's individual desire for support in the decision-making process. Most women maintained that family support, particularly from their partners, was very important. In reflecting on her husband's initial reluctance for her to have a prophylactic mastectomy, one woman wondered, "I don't know if he'd have said to do it if I would have made the decision earlier." Most women perceived their partners' attitude in supporting them in whatever decision they made as helpful, yet one woman stated, "That's what was frustrating to me. . . . If you love me, tell me to have the surgeries so I won't get sick, you know." For this woman, her supportive needs were not met based on her own preference.

The degree to which women wanted and received support from friends varied. One woman described how her coworkers were not encouraging of the idea of a prophylactic mastectomy. "They looked at me like I was from Mars, they didn't understand, you know." However, the opinions did not matter to her. "I'm the type of person who never really cared what anybody thinks." Many women stressed how helpful it was to talk to "women who have been there" and particularly with someone similar in age and life situation. One woman said, "Even if you read a book, speak to your husband, speak to a counselor, it's not the same as someone who went through the whole experience."

Body-image concerns were interconnected with partner support as well as the potential for reconstruction. For some women, the loss of breasts was not very significant. "To me, breasts don't make who you are as a person." Another said, "In any case, for me . . . it was not so important. . . . It was more important to save my life." However, a number of women did express concerns. "Body image and sexuality [are the] biggest factors for me. . . . We're so aware of our body image and what it represents, not only to us, but to society at large." If the partner had no concerns related to body image, the decision toward prophylactic mastectomy was clearer. One woman said, "My husband would rather have me alive without breasts than dying from cancer." Another said, "Your breasts aren't . . . what makes a marriage. . . . It's two people together . . . understanding and being there for each other. Body doesn't matter." The availability of reconstruction also helped to buffer body-image concerns. One woman said, "If I couldn't have a reconstruction, I might have thought about it twice maybe." Others said the following.

I definitely knew I wanted to have reconstruction. . . . I wanted to feel as much of a woman as possible, and feel as complete as possible, knowing that there is going to be this major loss. . . . It's an amputation, you know.

Reconstruction was a big factor. . . . I so desperately wanted to wake up and have breasts of some sort.

**Thoughts of the future:** In making the decision to have a prophylactic mastectomy, women clearly expressed not wanting to develop breast cancer or have a recurrence. One participant linked this to quality of life in terms of reducing the ever-present worry of cancer.

I didn't want to walk around for whatever time I have left thinking about when am I getting breast cancer. . . . Worrying about getting breast cancer is not a way to live, there are other things in your life besides focusing on that all the time.

Many women said that they did not want to die. "I was ready to do anything that was going to help me because my biggest fear was I was [going to] die, you know, when I was first diagnosed." For women with children, the fear often was expressed in the desire to be alive for them. One said, "I lived through losing a mother . . . and having younger siblings, having all the responsibilities on my shoulders at a young age, I didn't want that to happen to my kids." Another said, "I would like to see my children grow up. I'm a grandmother now, I never thought I would ever see that." Thoughts of the future were highly linked to the pivotal point.

## Pivotal Point

Testing positive for a mutation, having a personal breast cancer diagnosis, or having a family member with breast cancer subsequent to the knowledge of one's carrier status were pivotal points when the decision to have a prophylactic mastectomy became clear. Prior ambivalence to having surgery was diminished. At the pivotal point, all women perceived that the benefits of having a prophylactic mastectomy exceeded any benefits of leaving the breasts intact. Although pivotal points were crucial for participants in making a decision, looking only at these events and ignoring the prior interaction between intrapersonal and contextual factors is not possible.

Pivotal points were closely related to participants' risk perception and thoughts of the future. They embodied the perception of real risk and urgency to act. After her gene test, one woman stated, "It's almost like a time bomb . . . if it's not now, like my sisters, it's going to be in a few years." Another said the following.

You know, it's like walking on the yellow line with a bunch of drunk drivers and oops, okay, he didn't hit me. Lucky. Oops, he didn't hit me. You know? But eventually some truck is going to plow you down. And that's the terrifying part.

After her breast cancer diagnosis, another participant said, "What are you playing with fire for? Is it, what is so important? Your life or your breast? Ummm, I'm sorry, *life*."

Women viewed prophylactic mastectomy as effective for breast cancer prevention. "The *real* guarantee, oh, it's

not 100%, even with the mastectomy . . . but my God, it's 95%." In comparing surveillance with prophylactic mastectomy, another said,

If I was [going to] develop breast cancer, they couldn't stop that right, right? . . . They could treat it if it happened but they couldn't stop it from happening. . . . So, I said to myself, the mastectomy will finally stop that from happening.

Interestingly, all participants felt their decision to have a prophylactic mastectomy was an easy one to make. Despite the challenges that many faced, a decisive moment was reached when the choice to have a prophylactic mastectomy was obvious. One woman stated, "[A breast cancer diagnosis] forces you to make a decision, in a sense, which was sort of already made for you." Another woman spoke about her choice after a breast cancer recurrence. "And then you're told it's back, ah, let me tell you, it's in my opinion, it's [the] easiest decision of my life." Yet another participant described the point in time in which she thought: "The decision was a no brainer, literally a no brainer."

Most women declared the decision as their own. Despite the influence of friends, family, and the medical team, they felt that the decision was ultimately only theirs to make. "Nobody can make this decision for me." Even though the participant had significantly relied on support from family and friends, her perception echoed that of others. "Other people *absolutely* did *not* have a role in the decision, it was *totally* 100% my decision."

## Discussion

To the authors' knowledge, this is the first published qualitative study examining the decision-making process of women carrying a *BRCA1* or *BRCA2* mutation who opted for prophylactic mastectomy. An important new insight lies in the concept of a pivotal point—an event in the lives of participants when the decision to have the procedure became definitive. Prior to the pivotal point, many internal and external factors combined to move women toward or away from the decision.

Making such an important decision is not likely to be a straightforward cognitive process of weighing pros and cons; emotions also come into play (Broadstock & Michie, 2000). Traditional ways of viewing decision making tend to neglect these multimodal interacting factors and, therefore, do not comprehensively capture decision-making processes (McCaul, Peters, Nelson, & Stefanek, 2005). The role of anxiety and worry associated with breast cancer risk is particularly salient in prophylactic surgery decisions (Schwartz, Peshkin, Tercyak, Taylor, & Valdimarsdottir, 2005). In reviewing how people can perceive and act on risk, Slovic, Peters, Finucane, and MacGregor (2005) discussed the ideas of "risk as feelings," arguing that affect is an integral

part of rational action and necessary for sound decision making. Intuition and feelings are particularly relevant (Broadstock & Michie, 2000; Ubel & Lowenstein, 1997) when uncertainty is involved and, therefore, are pertinent in making decisions related to probabilistic cancer risk and prevention.

The perspective provides insight into understanding the nature of potential pivotal points found in the current study. The decision to have prophylactic mastectomy was made with logical connections and affective considerations. After integrating individual characteristics and preferences with their personal circumstances, the women came to a point of clarity to have a prophylactic mastectomy. The clarity took place in the context of either a mutation-positive gene test outcome or a breast cancer diagnosis in themselves or a family member once they knew of their mutation-positive status. At pivotal points, perceptions of breast cancer risk became very real, leading to significant worry and fear, which, in turn, prompted the decision to have mastectomy. The benefits of removing the breasts were perceived to outweigh any advantages of keeping them.

Why some women chose to have a prophylactic mastectomy following a mutation-positive result and others decided after receiving a breast cancer diagnosis is unclear. Perhaps women in the first group had a lower tolerance for uncertainty, and testing positive for a *BRCA1* or *BRCA2* mutation embodied a tangible representation of their risk. Alternately, the decision could be related to the woman's relative threat appraisal at that moment. Note that all women, regardless of their decision-making trajectories, consistently made decisions based on what they believed to be in their best interest.

The current study demonstrates that decision making does not occur separately from other aspects of women's lives. The process is embedded in complex interactions between women and their real-life situations, including events from the past and thoughts about the future. Although interactions between intrapersonal and contextual factors that occur during the decision-making process have not been described previously, the idea of connection and match between the person and the environment is a component of the developmental health framework (Gottlieb & Gottlieb, 2007). The issues clearly emerged within the current inquiry with a rich description in terms of their nature and impact.

Body image in relation to prophylactic mastectomy has been the subject of past research, but with a focus on psychosocial adaptation after surgery (Frost et al., 2005; McGaughey, 2006; Metcalfe, Esplen, Goel, & Narod, 2004). In a mixed-method study, Bebbington Hatcher and Fallowfield (2003) reported that husbands' negative attitudes toward prophylactic mastectomy may have been intertwined with body image for a few women. However, in the current study, body image emerged as

an influencing factor for women in their deliberation to have mastectomies. The explicit relationship between body image and partner support has not been described previously. One may reasonably expect that women consider the sexual connotations of their breasts in light of their spouse's opinion. The current study also corroborates the findings of other studies that highlight the importance of breast reconstruction in the decision to have prophylactic mastectomy (Frost et al., 2005; Metcalfe et al., 2004; Rolnick et al., 2007).

Other studies have found physician recommendation to be a significant predictor of undergoing prophylactic mastectomy (Schwartz et al., 2004). Similar to findings pertaining to surgical decision making for cancer treatment (Hack et al., 2006; Janz et al., 2004; Kenny et al., 1999; Lacey, 2002), physician recommendation was found to be moderated by women's personalities and their relative desires for physician support. However, issues surrounding treatment circumstances and prevention must be distinguished. Medical advice is less likely to be directive in the latter situation, with the decision arguably being less straightforward and bearing added decisional responsibility on the women.

## Limitations

The current study had several limitations. First, most of the data gathered relied on participants' recall of events. The relatively small sample from a unique cancer center reduced the representativeness of the findings. In addition, focusing solely on carriers of a *BRCA1* or *BRCA2* gene mutation who have chosen to have a prophylactic mastectomy restricts the breadth of what findings could have emerged. For example, little is known about decision making in mutation carriers who have opted against prophylactic mastectomy or in women who are not gene carriers and have undergone prophylactic mastectomy. In addition, the extent to which differing situational variables would have affected the same woman in her decision making remains unknown.

## Conclusion and Nursing Implications

The current study emphasized several important implications for practice in terms of providing support to women who know their carrier status and are faced with having to decide whether or not to undergo a prophylactic mastectomy. In particular, the provision of information and helping women to weigh the pros and cons may be insufficient. Interventions also must address affective and contextual components of the decision. Strategies such as active listening and sharing empathic highlights have been effective in increasing self-awareness and validating experiences (Egan, 2007). The use of illness narrative also is emerging as a way to facilitate the processes (Carlick & Biley, 2004). An



awareness of factors typically considered and how they interact as well as knowledge of the existence of pivotal points may assist nurses and other healthcare providers to better understand how women decide, thus facilitating the provision of support.

The benefit of receiving support from other women who have lived the experience was clearly expressed by participants. This underscores findings by Patenaude et al. (2008), who found that the informational and emotional value of peer consultation were most helpful if shared by similar others. Nurses or healthcare providers could link women who have faced similar decisions under comparable circumstances. To date, little is known about the effectiveness of this type of support in women's decision-making trajectory.

Future studies could include alternate qualitative approaches, such as grounded theory methodology or a longitudinal design. Additional work could involve gene-mutation carriers who have not had prophylactic mastectomy. Once the decision-making processes are better understood, targeted interventions aimed at enhancing support provided to women facing prophylactic mastectomy could be developed and empirically tested.

*The authors gratefully acknowledge the women who shared their stories and demonstrated extraordinary strength in the process of dealing with their breast cancer risk status. Authors McQuirter and Castiglia gratefully acknowledge advisors Carmen G. Loiselle, N, PhD, and Nora Wong, MS, for conceptualizing and securing funding for this study and providing the opportunity to interview the participants. In addition, they are grateful to professors Margaret Purden, PhD, Nancy Feeley, PhD, and Janet Rennick, PhD, for providing constructive feedback, instruction on qualitative research, and guidance in meeting master's degree requirements.*

Megan McQuirter, MSc(A), is a nurse candidate in the Cardiac Care Unit at Royal Victoria Hospital in Montreal, Quebec, Canada; Luisa Luciani Castiglia, BScN, CON(C), is a clinical nurse educator in cancer care and dialysis at St. Mary's Hospital in Montreal; Carmen G. Loiselle, N, PhD, is an associate professor in the School of Nursing at McGill University, leader of the Psychosocial Oncology Research Training program, and senior *Fonds de la Recherche en Santé du Québec* researcher at the Jewish General Hospital, all in Montreal; and Nora Wong, MS, is a faculty lecturer in the Departments of Medicine and Human Genetics at McGill University and a genetic counselor at the Jewish General Hospital. This research was funded by the Weekend to End Breast Cancer and the Jewish General Hospital Foundation. McQuirter can be reached at [megan.mcquirter@mail.mcgill.ca](mailto:megan.mcquirter@mail.mcgill.ca), with copy to editor at [ONFEditor@ons.org](mailto:ONFEditor@ons.org). (Submitted March 2009. Accepted for publication August 17, 2009.)

Digital Object Identifier: 10.1188/10.ONF.313-320

## References

- Bebbington Hatcher, M., & Fallowfield, L.J. (2003). A qualitative study looking at the psychosocial implications of bilateral prophylactic mastectomy. *Breast*, 12, 1-9. doi: 10.1016/S0960-9776(02)00135-2
- Bleiker, E.M., Hahn, D.E., & Aaronson, N.K. (2003). Psychosocial issues in cancer genetics: Current status and future directions. *Acta Oncologica*, 42, 276-286. doi: 10.1080/02841860310004391
- Broadstock, M., & Michie, S. (2000). Processes of patient decision making: Theoretical and methodological issues. *Psychology and Health*, 15, 191-204. doi: 10.1080/08870440008400300
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461-466.
- Carlick, A., & Biley, F.C. (2004). Thoughts on the therapeutic use of narrative in the promotion of coping in cancer care. *European Journal of Cancer Care*, 13, 308-317. doi: 10.1111/j.1365-2354.2004.00466.x
- Carnevale, F.A. (2002). Authentic qualitative research and the quest for methodological rigour. *Canadian Journal of Nursing Research*, 34, 121-128.
- Chen, S., & Parmigiani, G. (2007). Meta-analysis of BRCA1 and BRCA2 penetrance. *Journal of Clinical Oncology*, 25, 1329-1333. doi: 10.1200/JCO.2006.09.1066
- De Leeuw, J.R., van Vliet, M.J., & Ausems, M.G. (2008). Predictors of choosing life-long screening or prophylactic surgery in women at high risk and moderate risk for breast and ovarian cancer. *Familial Cancer*, 7, 347-359. doi: 10.1007/s10689-008-9189-5
- Egan, G. (2007). *The skilled helper: A problem-management and opportunity-development approach to helping* (8th ed.). Pacific Grove, CA: Brooks/Cole.
- Eisinger, F., Julian-Reynier, C., Stoppa-Lyonnet, D., Lasset, C., & Nogues, C. (2000). Acceptability of prophylactic mastectomy in cancer-prone women. *JAMA*, 283, 197-203. doi: 10.1001/jama.283.2.202
- Frost, M.H., Slezak, J.M., Tran, N.V., Williams, C.I., Johnson, J.L., Woods, J.E., . . . Hartmann, L.C. (2005). Satisfaction after contralateral prophylactic mastectomy: The significance of mastectomy type, reconstructive complications, and body appearance. *Journal of Clinical Oncology*, 23, 7849-7856. doi: 10.1200/JCO.2005.09.233
- Gottlieb, L.N., & Gottlieb, B. (2007). The developmental/health framework within the McGill Model of Nursing: "Laws of nature" guiding whole person care. *Advances in Nursing Science*, 30, E43-E57.
- Hack, T.F., Degner, L.F., Watson, P., & Sinha, L. (2006). Do patients benefit from participating in medical decision-making? Longitudinal follow-up of women with breast cancer. *Psycho-Oncology*, 15, 9-19. doi: 10.1002/pon.907
- Hallowell, N. (1998). "You don't want to lose your ovaries because you think 'I might become a man'": Women's perceptions of prophylactic surgery as a cancer risk management option. *Psycho-Oncology*, 7, 263-275.
- Janz, N.K., Wren, P.A., Copeland, L.A., Lowery, J.C., Goldfarb, S.L., & Wilkins, E.G. (2004). Patient-physician concordance: Preferences, perceptions, and factors influencing the breast cancer surgical decision. *Journal of Clinical Oncology*, 22, 3091-3098. doi: 10.1200/JCO.2004.09.069
- Kenny, P., Quine, S., Shiell, A., & Cameron, S. (1999). Participation in treatment decision-making by women with early stage breast cancer. *Health Expectations*, 2, 159-168. doi: 10.1046/j.1369-6513.1999.00050.x
- Kurian, A.W., Hartman, A.R., Mills, M.A., Ford, J.M., Daniel, B.L., & Plevritis, S.K. (2005). Opinions of women with high inherited breast cancer risk about prophylactic mastectomy: An initial evaluation from a screening trial including magnetic resonance imaging and ductal lavage. *Health Expectations*, 8, 221-233. doi: 10.1111/j.1369-7625.2005.00333.x
- Lacey, M.D. (2002). The experience of using decisional support aids by patients with breast cancer. *Oncology Nursing Forum*, 29, 1491-1497. doi: 10.1188/02.ONF.1491-1497
- Lloyd, S.M., Watson, M., Oaker, G., Sacks, N., Rovere, U.Q., & Gui, G. (2000). Understanding the experience of prophylactic bilateral mastectomy: A qualitative study of ten women. *Psycho-Oncology*, 9, 473-485.
- Lodder, L.N., Frets, P.G., Trijsburg, R.W., Meijers-Heijboer, E.J., Klijn, J.G., Seynaeve, C., . . . Niermeijer, M.F. (2002). One year follow-up of women opting for presymptomatic testing for BRCA1 and BRCA2: Emotional impact of the test outcome and decisions on risk

- management (surveillance or prophylactic surgery). *Breast Cancer Research and Treatment*, 73, 97–112. doi: 10.1023/A:1015269620265
- Loiselle, C.G., Profetto-McGrath, J., Polit, D.F., & Beck, C.T. (2007). *Canadian essentials of nursing research* (2nd ed.). Philadelphia, PA: Lippincott Williams and Wilkins.
- McCaul, K.D., Peters, E., Nelson, W., & Stefanek, M. (2005). Linking decision-making research and cancer prevention and control: Important themes. *Health Psychology*, 24(4, Suppl.), S106–S110. doi: 10.1037/0278-6133.24.4.S106
- McCullum, M., Botorff, J.L., Kelly, M., Kieffer, S.A., & Balneaves, L.G. (2007). Time to decide about risk-reducing mastectomy: A case series of BRCA1/2 gene mutation carriers. *BioMed Central Women's Health*, 7(3), 1–9.
- McGaughey, A. (2006). Body image after bilateral prophylactic mastectomy: An integrative literature review. *Journal of Midwifery and Women's Health*, 51, E45–E49. doi: 10.1016/j.jmwh.2006.07.002
- Meiser, B., Butow, P., Friedlander, M., Schnieden, V., Gattas, M., Kirk, J., . . . Tucker, K. (2000). Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. *Journal of Clinical Oncology*, 18, 2250–2257.
- Meiser, B., Butow, P., Price, M., Bennet, B., Berry, G., & Tucker, K. (2003). Attitudes to prophylactic surgery and chemoprevention in Australian women at increased risk for breast cancer. *Journal of Women's Health*, 12, 769–778. doi: 10.1089/154099903322447738
- Metcalfe, K.A., Esplen, M.J., Goel, V., & Narod, S.A. (2004). Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy. *Psycho-Oncology*, 13, 14–25. doi: 10.1002/pon.726
- Metcalfe, K.A., Foulkes, W.D., Kim-Sing, C., Ainsworth, P., Rosen, B., Armel, S., . . . Narod, S.A. (2008). Family history as a predictor of uptake of cancer preventive procedures by women with BRCA1 or BRCA2 mutation. *Clinical Genetics*, 73, 474–479. doi: 10.1111/j.1399-0004.2008.00988.x
- Metcalfe, K.A., Lubinski, J., Ghadirian, P., Lynch, H., Kim-Sing, C., Friedman, E., . . . Narod, S.A. (2008). Predictors of contralateral prophylactic mastectomy in women with a BRCA1 or BRCA2 mutation: The hereditary breast cancer clinical study group. *Journal of Clinical Oncology*, 26, 1093–1097. doi:10.1200/JCO.2007.12.6078
- Metcalfe, K.A., Poll, A., O'Connor, A., Gershman, S., Armel, S., Finch, A., . . . Narod, S.A. (2007). Development and testing of a decision aid for breast cancer prevention for women with a BRCA1 or BRCA2 mutation. *Clinical Genetics*, 72, 208–217. doi: 10.1111/j.1399-0004.2007.00859.x
- Morse, J.M., & Field, P.A. (1995). Principles of data collection. In *Qualitative research methods for health professionals* (2nd ed., pp. 89–124). Thousand Oaks, CA: Sage.
- National Cancer Institute. (2008). *Genetics of breast and ovarian cancer*. Retrieved from <http://www.cancer.gov/cancertopics/pdq/genetics/breast-and-ovarian/HealthProfessional/page3>
- Patenaude, A.F., Orozco, S., Li, X., Kaelin, C.M., Gadd, M., Matory, Y., . . . Garber, J.E. (2008). Support needs and acceptability of psychological and peer consultation: Attitudes of 108 women who had undergone or were considering prophylactic mastectomy. *Psycho-Oncology*, 17, 831–843. doi: 10.1002/pon.1279
- Press, N., Reynolds, S., Pinsky, L., Murthy, V., Leo, M., & Burke, W. (2005). "That's like chopping off a finger because you're afraid it might get broken": Disease and illness in women's views of prophylactic mastectomy. *Social Science and Medicine*, 61, 1106–1117.
- Ray, J.A., Loescher, L.J., & Brewer, M. (2005). Risk-reduction surgery decisions in high-risk women seen for genetic counseling. *Journal of Genetic Counseling*, 14, 473–484. doi: 10.1007/s10897-005-5833-5
- Rebbeck, T.R., Friebe, T., Lynch, H.T., Neuhausen, S.L., van 't Veer, L., Garber, J.E., . . . Weber, B.L. (2004). Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: The PROSE study group. *Journal of Clinical Oncology*, 22, 1055–1062. doi: 10.1200/JCO.2004.04.188
- Rogozinska-Szczepka, J., Utracka-Hutka, B., Grzybowska, E., Maka, B., Nowicka, E., Smok-Ragankiewicz, A., . . . Wojciechowska-Lacka, A. (2004). BRCA1 and BRCA2 mutations as prognostic factors in bilateral breast cancer patients. *Annals of Oncology*, 15, 1373–1376. doi: 10.1093/annonc/mdh352
- Rolnick, S.J., Altschuler, A., Nekhlyudov, L., Elmore, J.G., Greene, S.M., Harris, E.L., . . . Fletcher, S.W. (2007). What women wish they knew before prophylactic mastectomy. *Cancer Nursing*, 30, 285–291. doi: 10.1097/01.NCC.0000281733.40856.c4
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334–340.
- Schwartz, M.D., Lerman, C., Brogan, B., Peshkin, B.N., Halbert, C.H., DeMarco, T., . . . Isaacs, C. (2004). Impact of BRCA1/BRCA2 counseling and testing on newly diagnosed breast cancer patients. *Journal of Clinical Oncology*, 22, 1823–1829. doi: 10.1200/JCO.2004.04.086
- Schwartz, M.D., Peshkin, B.N., Tercyak, K.P., Taylor, K.L., & Valdimarsdottir, H. (2005). Decision making and decision support for hereditary breast-ovarian cancer susceptibility. *Health Psychology*, 24(4, Suppl.), S78–S84. doi: 10.1037/0278-6133.24.4.S78
- Schwartz, M.D., Valdimarsdottir, H.B., DeMarco, T.A., Peshkin, B.N., Lawrence, W., Rispoli, J., . . . Komaridis, K. (2009). Randomized trial of a decision aid for BRCA1/BRCA2 mutation carriers: Impact on measures of decision making and satisfaction. *Health Psychology*, 28, 11–19. doi: 10.1037/a0013147
- Slovic, P., Peters, E., Finucane, M.L., & MacGregor, D.G. (2005). Affect, risk, and decision making. *Health Psychology*, 24(4, Suppl.), S35–S40. doi: 10.1037/0278-6133.24.4.S35
- Stefanek, M., Enger, C., Benkendorf, J., Honig, S.F., & Lerman, C. (1999). Bilateral prophylactic mastectomy decision making: A vignette study. *Preventive Medicine*, 29, 216–221. doi: 10.1006/pmed.1999.0524
- Stefanek, M.E., Helzlsouer, K.J., Wilcox, P.M., & Houn, F. (1995). Predictors of and satisfaction with bilateral prophylactic mastectomy. *Preventive Medicine*, 24, 412–419. doi:10.1006/pmed.1995.1066
- Ubel, P.A., & Lowenstein, G. (1997). The role of decision analysis in informed consent: Choosing between intuition and systematicity. *Social Science and Medicine*, 44, 647–656. doi: 10.1006/pmed.1995.1066
- Uric, I., Verhoef, L.C., Stalmeier, P.F., & van Daal, W.A. (2000). Prophylactic mastectomy or screening in women suspected to have the BRCA1/2 mutation: A prospective pilot study of women's treatment choices and medical decision-analytic recommendations. *Medical Decision Making*, 20, 251–262. doi: 10.1177/0272989X0002000301
- Vadaparampil, S.T., Wey, J.P., & Kinney, A.Y. (2004). Psychosocial aspects of genetic counseling and testing. *Seminars in Oncology Nursing*, 20, 186–195. doi: 10.1177/0272989X0002000301
- van Dijk, S., Otten, W., Zoetewij, M.W., Timmermans, D.R., van Asperen, C.J., Breuning, M.H., . . . Kievit, J. (2003). Genetic counselling and the intention to undergo prophylactic mastectomy: Effects of a breast cancer risk assessment. *British Journal of Cancer*, 88, 1675–1168. doi: 10.1038/sj.bjc.6600988
- van Dijk, S., van Roosmalen, M., Otten, W., & Stalmeier, P.F. (2008). Decision making regarding prophylactic mastectomy: Stability of preferences and the impact of anticipated feelings of regret. *Journal of Clinical Oncology*, 26, 2358–2363. doi: 10.1200/JCO.2006.10.5494
- van Roosmalen, M.S., Stalmeier, P.F., Verhoef, L.C., Hoekstra-Weebers, J.E., Oosterwijk, J.C., Hoogerbrugge, N., . . . van Daal, W.A. (2004a). Impact of BRCA1/2 testing and disclosure of a positive test result on women affected and unaffected with breast or ovarian cancer. *American Journal of Medical Genetics. Part A*, 124A, 346–355.
- van Roosmalen, M.S., Stalmeier, P.F., Verhoef, L.C., Hoekstra-Weebers, J.E., Oosterwijk, J.C., Hoogerbrugge, N., . . . van Daal, W.A. (2004b). Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. *Journal of Clinical Oncology*, 22, 3293–3301.
- van Sprundel, T.C., Schmidt, M., Rookus, M., Brohet, R., van Asperen, C.J., Rutgers, E., . . . Tollenaar, R.A. (2005). Risk reduction of contralateral breast cancer and survival after contralateral prophylactic mastectomy in BRCA1 or BRCA2 mutation carriers. *British Journal of Cancer*, 93, 287–292. doi: 10.1038/sj.bjc.6602703
- Zakaria, S., & Degnim, A.C. (2007). Prophylactic mastectomy. *Surgical Clinics of North America*, 87, 317–331. doi: 10.1016/j.suc.2007.01.009