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

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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.

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 mange 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 (Metcalfe, 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 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;