PSYCHOSOCIAL FACTORS THAT INFLUENCE DECISION MAKING ABOUT PROPHYLACTIC SURGERY

*Carolyn Y. Fang, Tamara McKenzie, Suzanne M. Miller and Mary B. Daly**

**División of Population Science Fox Chase Cancer Center*

Resumen

Hemos revisado la literatura empírica acerca de los factores psicosociales que influyen en las decisiones de las mujeres acerca de someterse a cirugía profiláctica. En total hemos identificado 34 estudios. La mayoría de ellos encuentran que la preocupación del cáncer específico y la percepción de riesgo ejercen una considerable influencia en la decisión tomada acerca de la cirugía profiláctica. Los elevados niveles de ansiedad por padecer un cáncer específico estaban positivamente relacionados con el interés y la intención de someterse a la cirugía. Además, el aumento de la percepción de riesgo estaba también asociado con un aumento del interés en la cirugía. Las mujeres citaban por otro lado asuntos referentes a la imagen corporal y la sexualidad, las responsabilidades familiares y las normas culturales como influyentes en el proceso de toma de decisiones. Varios de los estudios han empezado a evaluar el impacto de la ayuda en la decisión y las intervenciones de counseling, pero estudios posteriores muestran la necesidad de evaluar a largo plazo, en un futuro más lejano, las implicaciones psicológicas, conductuales y médicas de estas intervenciones. El consejo decisional y la clasificación de las preferencias pueden ser útiles para facilitar la selección entre diferentes alternativas comportamentales y en mejorar los resultados de los pacientes.

Palabras clave: Toma de decisiones, cirugía profiláctica, ansiedad relacionada con el cáncer, percepción de riesgo, imagen corporal.

Abstract

We reviewed the empirical literature on psychosocial factors influencing women's decisions to undergo prophylactic surgery. A total of 34 studies were identified. The majority of studies found that women's cancer-specific worries and risk perceptions exerted considerable influence in decision making about prophylactic surgery. Higher levels of cancer-specific anxiety were positively associated with interest in and intention to undergo surgery. In addition, greater perceived risk was also associated with greater interest and uptake of prophylactic surgery. Women also cited issues concerning body image and sexuality, familial responsibilities, and cultural norms as influencing the decision-making process. Several studies have begun to evaluate the impact of decision aids and counseling interventions, but additional studies are still needed to evaluate the long-term psychosocial, behavioral, and medical implications of these interventions. Decision counseling and preference clarification may be useful in facilitating the selection between different behavioral alternatives and in enhancing patient outcomes.

Keywords: Decision making, prophylactic surgery, cancer-related anxiety, perceived risk, body image.

INTRODUCTION

In the mid-1990s, the identification of the *BRCA1* and *BRCA2* genes created the possibility of testing for inherited susceptibility to breast and ovarian cancer. Women who are identified as *BRCA1/2* mutation carriers are known to have an increased risk of developing breast and ovarian cancer. Women who carry mutations in either gene have a risk of breast cancer that has been reported to be as high as 85% by the age of 70 years[1]. In women with *BRCA1* mutations, the lifetime risk level of developing ovarian cancer has been estimated to be between 15% and 65%[2,3].

Correspondencia:

Carolyn Y. Fang, Ph. D.
Fox Chase Cancer Center
510 Township Line Road
Cheltenham, Pennsylvania 19012. USA
E-mail: carolyn.fang@fccc.edu

BREAST CANCER AND PROPHYLACTIC MASTECTOMY

Women at risk for breast/ovarian cancer are faced with a number of decisions concerning cancer screening and prevention options. These options include chemoprevention, close surveillance, and prophylactic surgery of the breasts and/or ovaries. Medically and psychologically, there are advantages and disadvantages associated with each of these options. With respect to chemoprevention, one study demonstrated that tamoxifen can reduce the incidence of breast cancer in healthy women at increased risk for the disease[4], although two other studies failed to confirm this finding[2,5]. In addition, the potential benefits of tamoxifen in reducing breast cancer risk are not established among *BRCA1/2* mutation carriers[6]. Breast cancer surveillance options for mutation carriers include clinical breast exams and mammography every 6-12 months. However, there is evidence that mammography may not be as effective in mutation carriers, possibly due to the fact that the women are screened at a younger age and have dense breast tissue[7].

Although the clinical option of prophylactic mastectomy (PM) remains controversial, data suggest that PM reduces the risk of breast cancer by > 90% in mutation carriers[8]. Therefore, physicians and at-risk women have expressed considerable interest in prophylactic surgery as a cancer risk reduction strategy. A recent review of the literature reported that the proportion of *BRCA1/2* carriers who chose prophylactic surgery over screening has been as high as 54% for prophylactic mastectomy[9].

However, there are medical and psychological limitations to prophylactic mastectomy. A major limitation of prophylactic mastectomy is the inability to remove all traces of glandular tissue, thus leaving residual tissue with neoplastic potential[10]. Additional limitations include the potential for physical side effects and psychological consequences that follow surgery, including postoperative pain, phantom sensations, feelings of depression, and negative impacts on body image and sexuality[10-13]. Consequently, the decision to go through with prophylactic surgery is a highly individual one.

OVARIAN CANCER AND PROPHYLACTIC OOPHORECTOMY

Ovarian cancer causes more deaths than any other cancer of the female reproductive system[14]. The high incidence of mortality associated with the disease is attributed to two main factors. First, early stage disease is not associated with clear, site-specific symptoms. Second, ovarian cancer surveillance regimens, which include pelvic examination, transvaginal ultrasound, and CA125 blood test, have relatively low sensitivity and specificity[15]. Hence, ovarian cancer is often not diagnosed until it has progressed to more advanced, less treatable stages[16].

Given the difficulty of early detection, women at increased risk for developing ovarian cancer may consider undergoing prophylactic oophorectomy. Prophylactic oophorectomy has been shown to significantly reduce ovarian cancer risk in the general population[17] and among women who carry a *BRCA1/2* mutation[18,19]. Moreover, accumulating evidence indicates that prophylactic oophorectomy also confers a reduction in risk for breast cancer in women who carry a BRCA1 mutation[18-20].

However, potential medical limitations and psychological consequences of the procedure may prevent women from choosing this option. For example, surgery may not completely eliminate cancer risk. Indeed, cases of post-oophorectomy intra-abdominal carcinomatosis (which histologically resembles ovarian cancer) have been reported in the literature[21-23]. Further, oophorectomy may not be a viable option for women who have not completed their childbearing. As women are postponing childbearing until later in life, the benefits of surgery in reducing cancer risk become less, because gains in life expectancy from

prophylactic oophorectomy decline with age at the time of surgery[24]. Finally, many women express concerns about the physical symptoms associated with premature menopause[25]. Thus, the decision of whether to undergo prophylactic surgery is often a difficult one to make.

Clearly, prophylactic surgery carries with it the potential for considerable physical and psychological consequences. For a subset of women, undergoing prophylactic surgery leads to adverse psychological consequences[26,27]. Some women have reported regrets and dissatisfaction with their decisions to undergo the procedure and poorer psychological functioning following surgery[26,28]. Therefore, it is important to understand the factors that influence women's decisions about prophylactic surgery in order to develop effective interventions and/or decision aids to enhance decision outcomes. In this article, we review the empirical literature on psychosocial factors influencing women's decisions to undergo prophylactic surgery to reduce cancer risk.

Decision Making about Prophylactic Surgery

A literature search was performed using PubMed and PsycLit with keywords "psychosocial," "psychological," "decision making," "prophylactic surgery," "prophylactic mastectomy," "prophylactic oophorectomy," "risk" and "cancer." Studies were also identified from previously published papers. The search included articles published in English prior to August, 2005. Only studies that explicitly focused on women's attitudes toward, or psychosocial factors influencing decision making about, prophylactic surgery were included. A total of 29 studies that examined psychosocial factors that influence women's decisions about prophylactic surgery were identified and are reviewed below.

Articles that solely examined psychological consequences *following* prophylactic surgery, the efficacy of prophylactic surgery in reducing cancer risk, healthcare practitioners' beliefs about and/or clinical recommendations concerning prophylactic surgery were not included in the summary table.

Cancer-related Anxiety and Worry

Twenty-one of the 29 studies reviewed identified or included assessments of cancer-related worry and anxiety as it related to women's interest in or uptake of prophylactic surgery. We describe studies of decision making for prophylactic mastectomy and prophylactic oophorectomy separately below.

Cancer-related worry and prophylactic mastectomy. Several qualitative studies of women at high risk for breast cancer have indicated that anxiety reduction is a primary factor in many women's decisions to undergo prophylactic mastectomy. Interviews of women who had already undergone bilateral prophylactic mastectomy (BPM) revealed that high levels of breast cancer worry contributed to their decision[28,29]. In interviews with 60 women who opted for BPM and 20 women who chose close surveillance[30], qualitative data analyses revealed that most women who opted for surgery were extremely anxious pre-operatively about developing breast cancer. Intrusive thoughts about breast cancer and obsessive checking for breast lumps were the most common symptoms of anxiety reported. The overriding expectation of women who chose BPM was a reduction in anxiety once the breast tissue was removed. In contrast, only a minority of women who chose close surveillance reported anxiety about developing breast cancer.

The findings from qualitative studies are consistent with data obtained during the decision-making process indicating that cancer-related worry is associated with women's interest in or intention to undergo BPM[31-33] and actual uptake of BPM[34-36]. The majority of these studies found that high levels of breast cancer anxiety were significantly and strongly associated with interest in[32] and intention to undergo BPM[31,33], as well as actual uptake of surgery[34,36].

Table 1. **Summary of studies that investigated psychosocial factors influencing decision making about prophylactic surgery**

Researcher	Year	Study Population	Study Design	Follow-up Period	Conclusions
Aziz et al. [78]	2005	323 unaffected women undergoing hysterectomy and considering PO	Cross-sectional Questionnaires	N/A	• Women choosing to undergo PO had significantly higher levels of anxiety than women who declined PO
Brain et al. [55]	2004	10 unaffected women at increased risk for ovarian cancer	Qualitative In-depth interviews	N/A	• Greatest obstacle to PO involved having to take time off work for the operation and postoperative recovery • Other barriers to PO included being unable to look after family members, a lack of practical support during postoperative recovery, onset of menopause • Reducing ovarian cancer risk was discussed as a factor • Age and loss of fertility were mentioned as factors in decision for or against surgery
Brandberg et al. [79]	2004	16 with previous breast cancer and 40 unaffected women at increased risk of breast cancer	Cross sectional Questionnaire and interview	N/A	• Women with breast cancer had more positive expectations for PM than unaffected women • Interest in prophylactic mastectomy was not found to be due to an overestimation of personal risk
Fang et al. [53]	2002	80 unaffected women at increased risk for ovarian cancer	Cross-sectional Questionnaire	N/A	• Higher levels of perceived risk were associated with greater intentions to undergo PO • Perceived benefits of surgery were associated with greater interest in PO
Fang et al. [54]	2003	76 unaffected women at increased risk for ovarian cancer	Cross-sectional Questionnaire	N/A	• Heightened risk perceptions were related to greater intentions to undergo PO • Reduction in fear of getting cancer and reduction in uncertainty were both associated with intention to have PO • Anxiety and depression were not associated with intention
Fry et al. [44]	2001	58 unaffected women at increased risk for ovarian cancer, 30 of whom underwent surgery and 28 who chose surveillance	Retrospective Questionnaire	Assessments were conducted 1-5 years post-surgery or for women who had been on an ovarian cancer registry for 1-5 years	• Reducing the risk of ovarian cancer, reducing cancer worry, and age were the three factors cited by most women as strongly influencing their decision making about PO • Women choosing surgery rated these factors as significantly more important than women in the screening groupa

Researcher	Year	Study Population	Study Design	Follow-up Period	Conclusions
					• Women in the screening group rated recovery time as significantly more important in their decision making than women in the surgical group • Issues concerning femininity were considered important factors in decision making by 11% of women
Hallowell [25]	1998	41 unaffected women at increased risk for breast or ovarian cancer	Longitudinal Semi-structured telephone interviews and in-person in-depth interviews.	Interviews were conducted prior to genetic counseling, 6-8 weeks post-counseling, and 12-months post-counseling	• The onset of menopause and negative effects upon sexual relationships were perceived as costs of undergoing oophorectomy and mastectomy, respectively • Perceived benefits of surgery included being able to fulfill familial obligations (by surviving longer), cancer risk reduction, and reduction of fear
Hallowell [39]	2000	23 high-risk women following PO	Retrospective In-depth interviews	Interviews were conducted 6 months to 25 years post-surgery	• The benefit of risk reduction was perceived to outweigh the emotional and physical costs of undergoing prophylactic oophorectomy • All women reported feeling a sense of relief following surgery and stated that they no longer perceived themselves as at-risk and no longer felt worried about developing cancer
Hallowell et al. [40]	2001	49 women with a family history of ovarian cancer — 23 women had undergone PO	Qualitative In-depth interviews	Interviews were conducted 6 months to 25 years post-surgery	• The experience of witnessing ovarian cancer in a close relative was a very influential factor in decision making • Many of the women undergoing screening indicated that they would consider surgery if they were confirmed as a mutation carrier
Hatcher et al[30]	2003	80 women at increased risk for breast cancer; 60 chose to undergo BPM	Qualitative In-depth interviews	For women who had surgery, interviews were conducted 6 and 18 months post-operatively	• Women choosing surgery were extremely anxious about developing breast cancer compared to decliners • Genetic test results did not appear to be related to decision making about surgery
Hatcher et al[35]	2005	143 women at increased risk for breast cancer; 79 chose to undergo BPM	Prospective Interviews and Questionnaires	Women undergoing BPM were interviewed again at 6 and 18	• Women who declined surgery had significantly higher scores on trait anxiety than women who had BPM • Women who had BPM tended to report higher lifetime risks of developing breast cancer than decliners

Researcher	Year	Study Population	Study Design	Follow-up Period	Conclusions
				months postoperatively; Women who declined surgery were interviewed 18 months post-initial interview	• Decliners were more likely to believe that screening was helpful
Hurley et al[41]	2001	94 unaffected women at increased risk for ovarian cancer	Cross-sectional Questionnaires	N/A	• Reducing anxiety/uncertainty was the strongest predictor of women's current interest in PO • Risks and benefits of surgery were also associated with women's interest in PO
Josephson et al[52]	2000	15 women at increased risk for breast cancer	Retrospective Interviews	Interviews were conducted 7-8 months post-surgery	• Decision making about surgery was influenced by actual risk reduction
Julian-Reynier et al[61]	2001	355 women (from France, England, and Quebec) who were either affected with breast or ovarian cancer or had a strong family history	Cross-sectional Questionnaire	N/A	• British women were more in favor of PO than French and Canadian women • British and Canadian women held more favorable attitudes toward PM than French women • Women who perceived they were at genetic risk held more positive attitudes toward prophylactic surgery than those who were not certain of their genetic risk
Lloyd et al[29]	2000	10 unaffected women who had prophylactic mastectomy	Qualitative Retrospective In-depth interviews	Interviews were conducted 6 weeks to 3 years post-surgery.	• Prior loss in the family from breast cancer was a key factor in decision making • Receiving genetic information influenced decisions • High levels of breast cancer worry and low confidence in early detection were cited as factors in decision making
Lodder et al[36]	2002	63 unaffected women undergoing *BRCA1/2* testing	Cross-sectional Questionnaire and telephone interviews	Interviews and questionnaires administered 12-months after disclosure of genetic test result	• Women opting for PM had significantly higher distress levels than carriers who opted for surveillance and non-mutation carriers • Mutation carriers choosing PM were younger and more likely to have young children

Researcher	Year	Study Population	Study Design	Follow-up Period	Conclusions
Meiser et al[42]	1999	95 unaffected women at increased risk for breast and/or ovarian cancer	Cross-sectional Questionnaire	N/A	• Women's interest in PO was associated with increased breast/ovarian cancer anxiety, but not objective cancer risk
Meiser et al[32]	2000	333 unaffected women at increased risk for breast cancer	Cross-sectional Questionnaire	N/A	• High levels of breast cancer anxiety and overestimation of one's breast cancer risk were associated with intention to undergo BPM • No association between objective breast cancer risk and intention was observed
Meiser et al[81]	2003	371 unaffected women at increased risk for breast cancer.	Cross-sectional Questionnaire	N/A	• Psychosocial factors (perceived risk, cancer distress) were not related to intention to undergo PM • Perceived risk of developing ovarian cancer, but not breast/ovarian cancer distress, was associated with intention to undergo PO
Montgomery et al[28]	1999	296 women who had undergone contralateral prophylactic mastectomy following breast cancer	Retrospective Questionnaire and interviews	Interviews were conducted 3 months to 43 years post-surgery	• Decisions to undergo prophylactic mastectomy were related not only to absolute risk of the disease but also to fear of developing more breast cancer
Schwartz et al[45]	2003	289 women at risk for breast/ovarian cancer undergoing genetic testing	Prospective Telephone interviews	Follow-up interviews conducted 1-year post-genetic testing	• In addition to mutation status, perceived risk for ovarian cancer, family history of ovarian cancer, age, older age, and ovarian cancer worries predicted uptake of PO
See et al[63]	2005	102 women in Singapore with a family history or personal history of breast cancer	Cross-sectional Questionnaires	N/A	• Age, perceived risk, and concerns about getting cancer were not related to women's attitudes towards prophylactic surgery
Stefanek et al[34]	1995	164 women at increased risk for breast cancer – 14 underwent BPM	Cross-sectional Questionnaires	N/A	• Subjective risk estimates, biopsy histories, and cancer-related worry influenced decision making • Women who opted fro BPM reported more breast cancer worry
Stefanek et al[31]	1999	233 women with and without family histories of breast cancer	Vignette study: Study participants were provided with a vignette of a woman at risk	N/A	• Family history of breast cancer was not directly related to selecting BPM • Cancer-related worry and the estimated 10-year risk of developing breast cancer were associated with the decision to choose BPM

Researcher	Year	Study Population	Study Design	Follow-up Period	Conclusions
Swisher et al[65]	2001	60 unaffected women at increased risk for ovarian cancer – 30 underwent PO and 30 chose surveillance	Qualitative In-depth telephone interview	N/A	• Factors influencing decision making for PO included concerns about the physical discomfort of surgery and recovery, menopause, and hormone replacement
Tiller et al[47]	2002	95 unaffected women at increased risk for breast/ovarian cancer – 22 underwent PO and 73 chose surveillance	Prospective Questionnaire	Follow-up assessments were conducted 3 years after women's initial attendance at a familial cancer clinic	• Age was a significant predictor of uptake of PO • Intention to have PO was significantly associated with actual uptake • No association between breast/ovarian cancer anxiety and uptake of PO • No association between objective risk and PO • Among women who underwent PO, there was a significant decrease in breast/ovarian cancer anxiety
van Dijk et al[33]	2003	241 women with a personal history or a family history of breast cancer	Prospective Questionnaire	Questionnaires completed before and after receiving genetic counseling	• Objective risk information and personal history of breast cancer did not influence women's intentions for PM • Higher levels of perceived risk and breast cancer worry were associated with greater intention to undergo PM
van Roosmalen, et al[50]	2004	368 affected and unaffected women undergoing *BRCA1/2* testing	Prospective Questionnaire	Questionnaires completed before and after receiving genetic test results	• Affected women valued PM and PO more highly than unaffected women and valued it higher at both time points
Wagner et al[82]	2000	138 *BRCA1/2* mutation carriers	Prospective Questionnaire	Follow-up assessments conducted 3 months following mutation result disclosure	• Factors influencing decisions against surgery included concern that PM would negatively affect quality of life and regarding PM as an invasion of privacy • Factors related to more positive attitudes toward PM included death of a close relative due to breast cancer, reduction in cancer risk, and fear of dying from cancer • There was a slightly higher acceptance of PO due to the patient's expectation that their quality if life was less likely to be impaired by this surgery

In contrast, one prospective study found that a significantly higher proportion of women who declined to undergo BPM reported high anxiety levels (as measured by the Spielberger State-Trait Anxiety Inventory[37] compared to women who underwent the surgery[35]. Among the women who did undergo BPM, anxiety levels decreased significantly from the pre-operative assessment to the 6-month postoperative assessment, whereas women who declined surgery reported no change in their anxiety levels[35]. It should be noted that cancer-specific worry was not specifically measured in this study. Therefore, the women who declined surgery had significantly higher scores on general anxiety, but may not necessarily have had higher levels of cancer-related anxiety. Indeed, previous studies have reported that women attending high-risk or familial cancer programs suffer from significant levels of general anxiety, but that general anxiety was not related to women's perceived vulnerability to cancer[38]. Thus, differential assessment of psychosocial constructs (i.e. cancer-specific anxiety vs. general anxiety) may account for the discrepant findings.

Cancer-related worry and prophylactic oophorectomy. Similar to BPM, the majority of studies of prophylactic oophorectomy (PO) found that cancer-related anxiety and worry was associated with greater interest in[25,39-44] and uptake of PO[45]. Indeed, reducing cancer-related worry was found to be the factor most strongly associated with women's interest in PO[41,44].

However, other studies have reported no significant difference in levels of cancer-specific worry between women who had undergone PO compared to women who opted to continue with ovarian cancer screening[46,47]. In a prospective study, Tiller and colleagues[47] found no association between breast/ovarian cancer anxiety at baseline (i.e. around the time of the woman's first attendance at a familial cancer clinic) and actual uptake of PO in the 3 years following baseline. However, women who underwent surgery tended to report significant reductions in anxiety post-surgery[43,47]. Thus, the findings are somewhat more mixed with respect to the role of cancer-specific worry and prophylactic oophorectomy. It may be that biological factors (such as childbearing plans) are much more powerful determinants of uptake of PO than cancer-related anxiety[47].

In sum, the bulk of the data indicate that women's cancer-specific worries exert considerable influence in decision making about prophylactic surgery, particularly mastectomy. Key differences in study findings, however, highlight the importance of clearly delineating between general and cancer-specific anxiety. In cross-sectional studies, cancer-specific anxiety was a strong determinant of interest in and intention to undergo surgery; however, over time, actual uptake of surgery may be more likely influenced by other factors. Therefore, conducting prospective studies with long-term follow-up is critical for obtaining a greater understanding of the contribution of cancer-related anxiety to the decision making process over time.

Cancer risk

BRCA1/2 mutation status and prophylactic surgery. Despite the current use of *BRCA1/2* testing to guide the clinical management of women with inherited risk for breast/ovarian cancer, there are few published data on uptake of prophylactic surgery following genetic testing. The few studies that exist indicate that a greater proportion of mutation carriers undergo prophylactic surgery compared to women receiving uninformative results and noncarriers[45]. However, the receipt of a positive test result (and the inferred greater cancer susceptibility that accompanies such test results) is not enough to influence decision making in favor of prophylactic surgery in many cases. A one-year follow-up of women who were unaffected carriers found that 3% chose to undergo PM and 13% chose to undergo PO in the year following *BRCA1/2* testing[48]. Uptake of prophylactic surgery

following identification of mutation status appears to be higher in other countries. In a study conducted in the Netherlands, 51% of unaffected carriers opted for BPM and 64% opted for PO[49]. Decision making about prophylactic surgery is not only influenced by mutation status, but also by a personal history of cancer. Among *BRCA1/2* mutation carriers, women with breast cancer reported greater intentions to obtain prophylactic surgery and valued prophylactic surgery more highly than unaffected mutation carriers[50].

Perceived risk and prophylactic mastectomy. For many women, the decision of whether or not to undergo prophylactic surgery is often not directly linked to one's objective risk level, but rather to one's perceived risk of developing cancer[51]. Across several studies, intention to undergo BPM was associated with perceived risk[33] and overestimation of one's perceived risk[32], but not with objective breast cancer risk. Thus, the impact of objective risk information on intention to undergo prophylactic mastectomy has been perceived to be rather limited[32,33].

Among women who are at increased risk for breast cancer, variations in perceived risk distinguished between those who were interested in prophylactic surgery and those who were not. For example, women who chose to undergo BPM tended to state that they would "inevitably develop cancer," thereby expressing high levels of perceived risk[35]. Women who self-reported that they were not interested in BPM gave lower risk estimates than those who were interested in surgery[34]. Similarly, in a vignette study, women's assessments of cancer risk were significant predictors of selecting BPM over surveillance[31]. In addition, the belief that surgery would significantly reduce breast cancer risk was found to be an important factor in the decision making process[35, 52].

Perceived risk and prophylactic oophorectomy. A number of studies have also identified perceived risk as positively associated with women's interest in or uptake of PO[25,39,40,53-55]. Across several qualitative studies, women listed high perceived risk as a primary reason to undergo PO and described cancer risk reduction as a perceived benefit of surgery[25,39,40]. Studies of women at familial risk for ovarian cancer confirmed these findings, such that higher levels of perceived risk were associated with intention to undergo PO within the following 12-month period[54].

Together, these studies indicate that perceived risk plays a major role in the decision-making process. Surgery appears to confer some psychological benefits, in terms of giving women "peace of mind"[39,56]. Women may also feel as though they are proactively choosing an intervention aimed at lowering their perceived cancer risk and extending their lives[56]. However, in some cases, the effects of perceived risk on women's decision making can be problematic because many women perceive their cancer risk, regardless of genetic mutation status, to be extremely high[56,57]. Women who base their healthcare decisions on these elevated risk perceptions need to be aware that they may be opting for a treatment that carries potentially significant long-term physical and psycholo-gical consequences.

Body image

Qualitative studies highlight the importance of issues concerning body image, femininity, and sexuality in women's consideration of prophylactic surgery. Women described the negative impact of surgery on body image and sexuality as a barrier to uptake of prophylactic surgery[25,58,59]. The physical consequences of PO, including surgically-induced menopause and the perceived acceleration of the aging process associated with menopause, have been cited as important barriers to uptake of PO[55]. However, prophylactic oophorectomy appears to be more acceptable to women than prophylactic mastectomy due to the perceived visible mutation associated with mastectomy[25,58]. Women have remarked that they are not interested in removing healthy tissue, regardless of genetic test

results[25], and that they are more willing to choose lifestyle changes (e.g., diet, exercise) over the perceived mutilation of their currently healthy bodies[58], despite a lack of evidence that these lifestyle changes can alter the risk of cancer in mutation carriers.

Attitudes towards body image, femininity, and preventive surgery are strongly influenced by cultural norms[60-62]. In countries where prophylactic surgery is considered "mutilation," such a strategy is not likely to be frequently utilized as a risk reduction strategy. Indeed, it has been found that women from the United Kingdom and Quebec were more in favor of prophylactic surgery at young ages than French women[61]. A study of women in Singapore, China found that over 41% would not consider prophylactic surgery[63]. Therefore, cultural differences in body image, femininity, and health beliefs can influence attitudes toward prophylactic surgery.

Demographic factors

Although the primary focus of this review is on the psychosocial factors that influence decision making about prophylactic surgery, it should be noted that certain demographic factors are known to play a key role in this process. We briefly discuss two key factors (parenthood and age) below.

Many women consider prophylactic surgery only after completing childbearing and lactation[24,25]. In a study of 139 unaffected mutation carriers, 55% chose preventative surgery rather than surveillance, and parenthood was the only variable that predicted this selection[64]. Similarly, among 411 mutation carriers, parenthood was a significant predictor for prophylactic mastectomy, but not for prophylactic oophorectomy[49]. A number of women cited the importance of surviving for their children and families as a reason for undergoing prophylactic surgery[25]. Women with young children and many familial responsibilities may be more motivated to undergo prophylactic surgery in order to prevent cancer and to ensure their long-term survival.

On the other hand, family responsibilities were also a commonly cited barrier to undergoing prophylactic surgery. Women frequently voiced their concerns about being unable to take care of family members and relinquishing the role of caretaker within the family during the post-surgical recovery period[55]. The practical considerations of surgery, including the physical discomfort of surgery[65], having to take time off from work, and the lack of practical support during postoperative recovery, were also cited as barriers to surgery. Women's concerns about surgical complications and the risks associated with anesthesia, and how these might negatively impact their ability to carry out their familial duties, also factored into their decision making.

A woman's age is also a significant predictor of interest in prophylactic surgery. A recent review found that women who chose PM over surveillance were younger and more likely to have children[9]. Older women women may be less motivated to have prophylactic surgery because they believe they have fewer familial responsibilities (i.e. raising young children) and lower life expectancy gains[66]. However, when older women do choose to undergo prophylactic surgery, they were found to be less negative about the onset of menopause than younger women[66].

For PO, older age was positively associated with uptake of surgery[9]. Women indicated that they were more likely to delay undergoing oophorectomy because of their age[55] and the physical consequences of surgery, including loss of fertility, the potential risk for cardiovascular disease and osteoporosis, and menopausal symptoms. Pre-menopausal women who chose to undergo prophylactic oophorectomy attributed more significance to the need for hormone replacement therapy than post-menopausal women did[44].

Age is a significant predictor of interest in prophylactic surgery in other cultures as well. Cross-culturally, 19.4% of women studied indicated that they would find prophylactic oophorectomy acceptable from

age thirty-five, in contrast to 59.4% of women who indicated that they would find prophylactic oophorectomy acceptable at age fifty[61]. With respect to prophylactic mastectomy, 16.3% found it an acceptable procedure at age thirty-five, whereas 28.7% found it acceptable at age fifty[61].

How can the decision-making process be enhanced?

Given that there is no clear consensus about which follow-up strategy (surveillance, chemoprevention, or prophylactic surgery) is optimal for any given patient, women may experience considerable distress during the decision-making process[67], as well as dissatisfaction and postdecision regret following the process[68]. Several studies have developed and examined the efficacy of various interventions and decision aids to enhance this complex process[69-75]. Five studies evaluated a decision-making program or decisional aid, one study evaluated an enhanced counseling intervention, and one study evaluated the effects of supportive-expressive group therapy. We briefly summarize these studies below.

A shared decision making program (SDMP) was developed for women believed to have a genetic predisposition to breast cancer[69,70]. The SDMP consisted of three to four sessions conducted at one- to two-week intervals and was fully evaluated among 54 women awaiting genetic test results. The sessions provided general information about breast cancer and risk factors for the disease, genetic testing, breast cancer screening, prophylactic mastectomy, and breast reconstruction. Women's preferences for surveillance and surgery were obtained at each of the first three sessions using the time tradeoff (TTO), which is a standard methodology for assessing individual preferences. In the last session, the results of the individual decision analyses were discussed and advice based upon the SDMP was offered. In general, women reported that the SDMP recommendations tended to agree with their intuitive choices[69].

Using a one-group pretest-posttest design, the SDMP was further evaluated among 72 women who were awaiting genetic test results and who were deciding between surveillance and prophylactic mastectomy[70]. Decision uncertainty, decision burden, subjective knowledge, and risk comprehension before and after the SDMP were assessed. Breast cancer concern and emotional reactions to the program information were also assessed. Overall, women were satisfied with the SDMP. Decision uncertainty and decision burden decreased from pretest to posttest, whereas subjective knowledge and risk comprehension increased. However, the SDMP was not beneficial for all participants. Women who scored high on "emotional reaction" to the information (i.e. found the information unpleasant, shocking, or frightening) tended to benefit less from the SDMP in terms of decision burden.

A similar shared decision making intervention (SDMI) was evaluated among 88 *BRCA1/2* mutation carriers who were deciding between screening and prophylactic surgery[72]. In this SDMI, two value assessment sessions were conducted where individual values for the two options (screening and surgery) were obtained using TTO methods. In the third session, individualized treatment information based on life expectancy (LE) and quality-adjusted life expectancy (QALE) was presented to the women. Specifically, individualized estimates of absolute gains and losses in LE and QALE for surgery compared with screening were presented to each woman. Overall, women in the SDMI group reported less distress over long-term follow-up compared to women in the control group. Although no differences were found between the two groups on actual treatment decision, the SDMI group did report holder stronger treatment preferences and were more likely to report having weighed the pros and cons compared to the control group. It was concluded that the SDMI improved decision making among unaffected *BRCA1/2* mutation carriers.

The impact of a decision aid was evaluated among 368 women undergoing *BRCA1/2* testing[73]. The decision aid presented detailed information on surveillance vs. surgery, as well as the physical, emotional, and social consequences of each option. The video presented interviews with other mutation carriers who had chosen either surveillance or surgery and described how they went through the decision-making process. Compared to women who received standard counseling alone, women receiving the decision aid felt more informed, were more satisfied with the information they received, and reported more accurate risk perceptions[73]. In addition, women receiving the decision aid expressed greater intentions to undergo prophylactic surgery and valued prophylactic surgery more highly than women in the control group[73].

Pell and colleagues[71] developed a computerized program to provide guidance to women on whether or not to undergo prophylactic oophorectomy. This clinical guidance program (CGP) presented a series of Markov models for each of four main outcomes relating to PO outcomes: cardiovascular disease, breast cancer, osteoporosis-related major fracture, and ovarian cancer. The CGP also calculated the net benefit or loss from oophorectomy as quality-adjusted life expectancy (QALE) using patient-specific risk factors and preferences for health outcomes. The program took about 20 minutes to run. Overall, women were able to use the CGP and expressed satisfaction with it. The CGP appeared to clarify the PO decision for most women, although for a subset of women, the explicit guidance statement was discrepant with women's previously held intentions[71].

One study evaluated the effects of an enhanced counseling intervention, in which the goal was to activate and "prelive" cognitive-affective reactions to receiving genetic test results in a supportive environment[75]. Following standard genetic counseling, 77 women undergoing *BRCA1/2* testing were randomized to receive either enhanced counseling or a general health information counseling session. The findings indicated that women who received the enhanced counseling intervention reported lower levels of cancer-related avoidant ideation. In addition, women in the intervention group were more likely to show interest in, and to undergo, prophylactic surgery compared to women in the control group.

The effects of supportive-expressive group therapy were examined among 70 *BRCA1/2* carriers using a within-subject design[74]. Women participated in 12 sessions of group therapy that lasted 6 months. Significant improvements in psychosocial functioning (i.e. cancer worry, anxiety, and depression) were observed from baseline to post-intervention. However, no change in knowledge levels or surveillance behaviors was observed from pre- to post-intervention, most likely due to a ceiling effect (knowledge and adherence to surveillance behaviors were high at baseline). A substantial proportion of women underwent prophylactic surgery by the time of the post-intervention assessment. Ten women had undergone PO, five women had undergone PM, and one woman was scheduled for surgery. In addition, seven women reported making decisions to not undergo prophylactic surgery (five women decided against PM, and two women decided against PO). All women who had requested support regarding decision-making about prophylactic surgery prior to the intervention reported completing their decision to either undergo surgery or to continue with surveillance. Because the study design did not include a control group, it is not possible to conclude that the intervention wholly contributed to these effects. However, the authors suggest that the group intervention was associated with improvements in psychosocial functioning and may have been helpful for supporting women's decision making about prophylactic surgery[74].

In sum, data obtained from these studies of decision counseling interventions and decision aids suggest that certain fea-

tures of the decision-making process may be enhanced as a result of these interventions. In particular, decisional uncertainty appeared to be reduced amongst participants in these interventions. However, given the limited number of studies that have been conducted to date, as well as the varied nature of the interventions evaluated, it is difficult to determine what the mechanism may be (e.g., improved risk comprehension, increased understanding of the benefits and consequences of each choice) that is responsible for these effects.

CONCLUSIONS

Decision making about cancer prevention and surveillance options can be challenging for women at high risk due to the complexity of the information presented and the myriad benefits and risks associated with each option that must be considered and weighed against each other. The empirical evidence suggests that patient decisions are strongly influenced by psychosocial factors such as cancer-specific worries, perceptions of cancer risk, and individual values concerning body image. Because cancer-specific anxiety and perceived risk are often reported to be elevated in this population, women are frequently faced with making decisions under conditions of high psychological distress and low comprehension, a poor combination for making well-informed and well-considered decisions. Recent studies have begun to evaluate the impact of decision support interventions and decision counseling on patient outcomes [76,77], but additional studies are still needed to evaluate the long-term psychosocial, behavioral, and medical implications of these decision aids and interventions. Decision counseling and preference clarification may ultimately be useful for helping healthcare providers better understand patient preferences in order to facilitate the selection between different behavioral alternatives and to enhance patient decision-making outcomes.

REFERENCES

1. Ford D, Easton DF, Stratton M, Narod S, Goldgar D, Devilee P, et al. Genetic heterogeneity and penetrance analysis of the BRCA1 and BRCA2 genes in breast cancer families. The Breast Cancer Linkage Consortium. Am J Hum Genet 1998; 62(3):676-89.
2. Liede A, Karlan BY, Baldwin RL, Platt LD, Kuperstein G, Narod SA. Cancer incidence in a population of Jewish women at risk of ovarian cancer. J Clin Oncol 2002; 20(6):1570-7.
3. Easton DF, Ford D, Bishop DT, Consortium TBCL. Breast and Ovarian Cancer Incidence in BRCA1-Mutation Carriers. Am J Hum Genet. 1995; 56:265-71.
4. Fisher B, Costantino JP, Wickerham DL, Redmond CK, Kavanah M, Cronin WM, et al. Tamoxifen for prevention of breast cancer: Report of the National Surgical Adjuvant Breast and Bowel Project P-1 Study. J Natl Cancer Inst 1998; 90:1371-88.
5. Veronesi U, Maisonneuve P, Costa A, Sacchini V, Maltoni C, Robertson C, et al. Prevention of breast cancer with tamoxifen: preliminary findings from the Italian randomised trial among hysterectomised women. Italian Tamoxifen Prevention Study. Lancet 1998; 352(9122):93-7.
6. King MC, Wieand S, Hale K, Lee M, Walsh T, Owens K, et al. Tamoxifen and breast cancer incidence among women with inherited mutations in BRCA1 and BRCA2: National Surgical Adjuvant Breast and Bowel Project (NSABP-P1) Breast Cancer Prevention Trial. Jama 2001; 286(18):2251-6.
7. Brekelmans CT, Seynaeve C, Bartels CC, Tilanus-Linthorst MM, Meijers-Heijboer EJ, Crepin CM, et al. Effectiveness of breast cancer surveillance in BRCA1/2 gene mutation carriers and women with high familial risk. J Clin Oncol 2001; 19(4): 924-30.
8. Rebbeck TR, Friebel T, Lynch HT, Neuhausen SL, van 't Veer L, Garber JE, et al. Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: the PROSE Study Group. J Clin Oncol 2004; 22(6):1055-62.

9. Wainberg S, Husted J. Utilization of screening and preventive surgery among unaffected carriers of a BRCA1 or BRCA2 gene mutation. Cancer Epidemiol Biomarkers Prev 2004; 13(12):1989-95.
10. Eisen A, Rebbeck T, Wood W, Weber B. Prophylactic surgery in women with a hereditary predisposition to breast and ovarian cancer. J. Clin Oncol. 2000; 18(9): 1980-95.
11. Dowdy SC, Stefanek M, Hartmann LC. Surgical risk reduction: prophylactic salpingo-oophorectomy and prophylactic mastectomy. Am J Obstet Gynecol 2004; 191(4):1113-23.
12. Mahon SM. Factors affecting genetic testing and decisions about prophylactic surgery. Clin J Oncol Nurs 2001; 5(3):117-20.
13. Van Oostrom I, Meijers-Heijboer H, Lodder LN, Duivenvoorden HJ, van Gool AR, Seynaeve C, et al. Long-term psychological impact of carrying a BRCA1/2 mutation and prophylactic surgery: a 5-year follow-up study. J Clin Oncol 2003; 21(20): 3867-74.
14. American Cancer Society. Cancer Facts and Figures 2005. Atlanta: American Cancer Society; 2005.
15. Rosenthal A, Jacobs I. Ovarian cancer screening. Seminars in Oncology 1998;25(3): 315-25.
16. Hensley ML, Castiel M, Robson ME. Screening for ovarian cancer: What we know, what we need to know. Oncology 2000; 14(11):1-18.
17. Rozario D, Brown I, Fung MFK, Temple L. Is incidental prophylactic oopherectomy an acceptable means to reduce the incidence of ovarian cancer? Am J Surg 1997; 173:495-8.
18. Kauff ND, Satagopan JM, Robson ME, Scheuer L, Hensley M, Hudis CA, et al. Risk-reducing salpingo-oophorectomy in women with a BRCA1 or BRCA2 mutation. N Engl J Med 2002; 346(21):1609-15.
19. Rebbeck TR, Lynch HT, Neuhausen SL, Narod SA, van't Veer L, Garber JE, et al. Prophylactic oophorectomy in carriers of BRCA1 or BRCA2 mutations. N Engl J Med 2002; 346(21):1616-22.
20. Rebbeck T, Levin A, Eisen A, Snyder C, Watson P, Cannon-Albright L, et al. Breast cancer risk after bilateral prophylactic oophorectomy in BRCA1 mutation carriers. J Natl Cancer Inst 1999; 91(17):1475-9.
21. Eltabbakh GH, Piver MS. Extraovarian primary peritoneal carcinoma. Oncology (Williston Park) 1998;12(6):813-9; discussion 820, 825-6.
22. Piver MS, Jishi M, Tsukada Y, Nava G. Primary peritoneal carcinoma after prophylactic oopherectomy in women with a family history of ovarian cancer. Cancer 1993;71:2751-5.
23. Rebbeck TR, Lynch HT, Neuhausen SL, Narod SA, Van't Veer L, Garber JE, et al. Prophylactic oophorectomy in carriers of BRCA1 or BRCA2 mutations. N Engl J Med 2002; 346(21):1616-22.
24. Schrag D, Kuntz KM, Garber JE, Weeks JC. Decision analysis — Effects of prophylactic mastectomy and oophorectomy on life expectancy among women with BRCA1 or BRCA2 mutations. New Engl J Med 1997; 336(20):1465-71.
25. Hallowell N. '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. Psychooncology 1998;7: 263-75.
26. Frost M, Schaid DJ, Seller T, Slezak J, Arnold P, Woods J, et al. Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. JAMA 2000; 284(3):319-24.
27. Payne D, Biggs C, Tran K, Borgen P, Massie M. Women's regrets after bilateral prophylactic mastectomy. Ann Surg Oncol 2000;7(2):150-4.
28. Montgomery L, Tran K, Heelan M, Van Zee K, Massie M, Payne D, et al. Issues of regret in women with contralateral prophylactic mastectomies. Ann Surg Oncol 1999; 6(6):546-52.
29. Lloyd SM, Watson M, Oaker G, Sacks N, Querci della Rovere U, Gui G. Understanding the experience of prophylactic bilateral mastectomy: a qualitative study of ten women. Psychooncology 2000;9(6): 473-85.

30. Hatcher MB. A qualitative study looking at the psychosocial implications of bilateral prophylactic mastectomy. Breast 2003;12: 1-9.
31. Stefanek M, Enger C, Benkendorf J, Flamm Honig S, Lerman C. Bilateral prophylactic mastectomy decision making: A vignette study. Prev Med 1999;29(3):216-21.
32. Meiser B, Butow P, Friedlander M, Schnieden V, Gattas M, Kirk J, et al. Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. J Clin Oncol 2000; 18(11):2250-7.
33. van Dijk S, Otten W, Zoeteweij MW, Timmermans DR, van Asperen CJ, Breuning MH, et al. Genetic counselling and the intention to undergo prophylactic mastectomy: effects of a breast cancer risk assessment. Br J Cancer 2003; 88(11):1675-81.
34. Stefanek ME, Helzlsouer KJ, Wilcox PM, Houn F. Predictors of and satisfaction with bilateral prophylactic mastectomy. Prev Med 1995; 24:412-9.
35. Hatcher MB, Fallowfield L, A'Hern R. The psychosocial impact of bilateral prophylactic mastectomy: prospective study using questionnaires and semistructured interviews. BMJ 2001; 322(7278):76.
36. Lodder LN, Frets PG, Trijsburg RW, Meijers-Heijboer E, Klijn JGM, Seynaeve C, et al. 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 Res Treat 2002; 73:97-112.
37. Spielberger CD, Gorsuch RL, Lushene RE. The State-Trait Anxiety Inventory. Palo Alto, CA: Consulting Psychologists Press; 1970.
38. Lindberg NM, Wellisch D. Anxiety and compliance among women at high risk for breast cancer. Ann Behav Med 2001; 23(4):298-303.
39. Hallowell N. A qualitative study of the information needs of high-risk women undergoing prophylactic oopherectomy. Psychooncology 2000; 9:486-95.
40. Hallowell N, Jacobs I, Richards M, Mackay J, Gore M. Surveillance or surgery? A description of the factors that influence high risk premenopausal women's decisions about prophylactic oophorectomy. J Med Genet 2001; 38 (10):683-91.
41. Hurley KE, Miller SM, Costalas JW, Gillespie D, Daly MB. Anxiety/uncertainty reduction as a motivation for interest in prophylactic oophorectomy in women with a family history of ovarian cancer. J Women's Health Gender-Based Med 2001; 10(2):189-99.
42. Meiser B, Butow P, Barratt A, Friedlander M, Gattas M, Kirk J, et al. Attitudes toward prophylactic oophorectomy and screening utilization in women at increased risk of developing hereditary breast/ovarian cancer. Gynecol Oncol 1999; 75(1):122-9.
43. Meiser B, Tiller K, Gleeson MA, Andrews L, Robertson G, Tucker K. Psychological impact of prophylactic oophorectomy in women at increased risk for ovarian cancer. Psychooncology 2000; 9:496-503.
44. Fry A, Rush R, Busby-Earle C, Cull A. Deciding about prophylactic oophorectomy: What is important to women at increased risk of ovarian cancer? Prev Med 2001; 33(6):578-85.
45. Schwartz MD, Kaufman E, Peshkin BN, Isaacs C, Hughes C, DeMarco T, et al. Bilateral prophylactic oophorectomy and ovarian cancer screening following BRCA1/BRCA2 mutation testing. J Clin Oncol 2003; 21(21):4034-41.
46. Fry A, Busby-Earle C, Rush R, Cull A. Prophylactic oophorectomy versus screening: psychosocial outcomes in women at increased risk of ovarian cancer. Psychooncology 2001; 10(3):231-41.
47. Tiller K, Meiser B, Butow P, Clifton M, Thewes B, Friedlander M, et al. Psychological Impact of Prophylactic Oophorectomy in Women at Increased Risk of Developing Ovarian Cancer: A Prospective Study. Gynecol Oncol 2002 ;86(2):212-9.
48. Lerman C, Hughes C, Croyle RT, Main D, Durham C, Snyder C, et al. Prophylactic surgery decisions and surveillance practices one year following BRCA1/2 testing. Prev Med 2000;31(1):75-80.
49. Meijers-Heijboer EJ, Verhoog LC, Brekelmans CT, Seynaeve C, Tilanus-Linthorst

MM, Wagner A, et al. Presymptomatic DNA testing and prophylactic surgery in families with a BRCA1 or BRCA2 mutation. Lancet 2000; 355(9220):2015-20.
50. van Roosmalen MS, Stalmeier PF, Verhoef LC, Hoekstra-Weebers JE, Oosterwijk JC, Hoogerbrugge N, et al. Impact of BRCA1/2 testing and disclosure of a positive test result on women affected and unaffected with breast or ovarian cancer. Am J Med Genet A 2004; 124(4):346-55.
51. Miller SM, Fang CY, Manne SL, Engstrom PF, Daly MB. Decision making about prophylactic oophorectomy among at-risk women: psychological influences and implications. Gynecol Oncol 1999; 75(3): 406-12.
52. Josephson U, Wickman M, Sandelin K. Initial experiences of women from hereditary breast cancer families after bilateral prophylactic mastectomy: a retrospective study. Eur J Surg Oncol 2000; 26(4):351-6.
53. Fang CY. The influence of attentional style and risk perceptions on intentions to undergo prophylactic oophorectomy among first-degree relatives. Psychol Health 2002; 17(3):356-76.
54. Fang CY, Miller SM, Malick J, Babb J, Engstrom PF, Daly MB. Psychosocial correlates of intention to undergo prophylactic oophorectomy among women with a family history of ovarian cancer. Prev Med 2003;3 7(5):424-31.
55. Brain K, Gravell C, France E, Fiander A, Gray J. An exploratory qualitative study of women's perceptions of risk management options for familial ovarian cancer: implications for informed decision making. Gynecol Oncol 2004; 92(3):905-13.
56. Elit L, Esplen MJ, Butler K, Narod S. Quality of life and psychosexual adjustment after prophylactic oophorectomy for a family history of ovarian cancer. Fam Cancer 2001; 1(3-4):149-56.
57. Alexander NE, Ross J, Sumner W, Nease RF, Jr., Littenberg B. The effect of an educational intervention on the perceived risk of breast cancer. J Gen Intern Med 1996; 11(2):92-7.
58. Di Prospero LS, Seminsky M, Honeyford J, Doan B, Franssen E, Meschino W, et al. Psychosocial issues following a positive result of genetic testing for BRCA1 and BRCA2 mutations: findings from a focus group and a needs-assessment survey. Cmaj 2001; 164(7):1005-9.
59. Metcalfe KA, Esplen MJ, Goel V, Narod SA. Psychosocial functioning in women who have undergone bilateral prophylactic mastectomy. Psychooncology 2004; 13(1): 14-25.
60. Julian-Reynier C, Eisinger F, Evans G, Foulkes W, Sobol H. Variation in prophylactic surgery decisions. Lancet 2000; 356(9242): 1687.
61. Julian-Reynier CM, Bouchard LJ, Evans DG, Eisinger FA, Foulkes WD, Kerr B, et al. Women's attitudes toward preventive strategies for hereditary breast or ovarian carcinoma differ from one country to another. Cancer 2001; 92:959-68.
62. Bouchard L, Blancquaert I, Eisinger F, Foulkes WD, Evans G, Sobol H, et al. Prevention and genetic testing for breast cancer: variations in medical decisions. Soc Sci Med 2004; 58(6):1085-96.
63. See HT, Cheung YB, Yong F, Khoo KS, Ang P. Acceptance of prophylactic surgery and chemoprevention of cancer in Singapore - a survey. Ann Acad Med Singapore 2005; 34(3):238-42.
64. Meijers-Heijboer H, van Geel B, van Putten WL, Henzen-Logmans SC, Seynaeve C, Menke-Pluymers MB, et al. Breast cancer after prophylactic bilateral mastectomy in women with a BRCA1 or BRCA2 mutation. N Engl J Med 2001; 345(3):159-64.
65. Swisher EM, Babb S, Whelan A, Mutch DG, Rader JS. Prophylactic oophorectomy and ovarian cancer surveillance. Patient perceptions and satisfaction. J Reprod Med 2001; 46(2):87-94.
66. Mahon SM. Factors affecting genetic testing and decisions about prophylactic surgery. Clin J Oncol Nurs 2001; 5(3):117-20.
67. Lobb EA, Butow PN, Barratt A, Meiser B, Gaff C, Young MA, et al. Communication and information-giving in high-risk breast cancer consultations: influence on patient outcomes. Br J Cancer 2004; 90(2):321-7.
68. Connolly T, Reb J. Regret in cancer-related decisions. Health Psychol 2005; 24(4 Suppl):S29-34.

69. Unic I, Stalmeier PF, Verhoef LC, van Daal WA. Assessment of the time-tradeoff values for prophylactic mastectomy of women with a suspected genetic predisposition to breast cancer. Med Decis Making 1998; 18(3):268-77.
70. Stalmeier PF, Unic IJ, Verhoef LC, Van Daal WA. Evaluation of a shared decision making program for women suspected to have a genetic predisposition to breast cancer: preliminary results. Med Decis Making 1999; 19(3):230-41.
71. Pell I, Dowie J, Clarke A, Kennedy A, Bhavnani V. Development and preliminary evaluation of a clinical guidance programme for the decision about prophylactic oophorectomy in women undergoing a hysterectomy. Qual Saf Health Care 2002; 11(1):32-8; discussion 38-9.
72. van Roosmalen MS, Stalmeier PF, Verhoef LC, Hoekstra-Weebers JE, Oosterwijk JC, Hoogerbrugge N, et al. Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. J Clin Oncol 2004; 22(16): 3293-301.
73. van Roosmalen MS, Stalmeier PF, Verhoef LC, Hoekstra-Weebers JE, Oosterwijk JC, Hoogerbrugge N, et al. Randomised trial of a decision aid and its timing for women being tested for a BRCA1/2 mutation. Br J Cancer 2004; 90(2):333-42.
74. Esplen MJ, Hunter J, Leszcz M, Warner E, Narod S, Metcalfe K, et al. A multicenter study of supportive-expressive group therapy for women with BRCA1/BRCA2 mutations. Cancer 2004; 101(10):2327-40.
75. Miller SM, Roussi P, Daly MB, Buzaglo JS, Sherman K, Godwin AK, et al. Enhanced Counseling for Women Undergoing BRCA1/2 Testing: Impact on Subsequent Decision Making About Risk Reduction Behaviors. Health Educ Behav 2005;32(5): 654-67.
76. Schwartz MD, Peshkin BN, Tercyak KP, Taylor KL, Valdimarsdottir H. Decision making and decision support for hereditary breast-ovarian cancer susceptibility. Health Psychol 2005; 24(4 Suppl):S78-84.
77. Myers RE. Decision counseling in cancer prevention and control. Health Psychol 2005; 24(4 Suppl):S71-7.
78. Aziz A. Differences in aspects of personality and sexuality between perimenopausal women making different choices regarding prophylactic oophorectomy and elective hysterectomy. Acta Obstetrica Gynaecol Scandinavia 2005;84:854-9.
79. Brandberg Y, Arver B, Lindblom A, Sandelin K, Wickman M, Hall P. Preoperative psychological reactions and quality of life among women with an increased risk of breast cancer who are considering a prophylactic mastectomy. Eur J Cancer 2004; 40(3):365-74.
80. Lim J, Macluran M, Price M, Bennett B, Butow P. Short- and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer. J Genet Couns 2004; 13(2):115-33.
81. Meiser B, Butow P, Price M, Bennett B, Berry G, Tucker K. Attitudes to prophylactic surgery and chemoprevention in Australian women at increased risk for breast cancer. J Womens Health (Larchmt) 2003; 12(8):769-78.
82. Wagner T, Moslinger R, Langbauer G, Ahner R, Group TAHBaOC, Fleischmann E, et al. Attitude towards prophylactic surgery and effects of genetic counseling in families with BRCA mutations. Br J Cancer 2000;82(7):1249-53.