

## What I wish I'd known before surgery: BRCA carriers' perspectives after bilateral salpingo-oophorectomy

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**Abstract** We retrospectively studied BRCA carriers with a history of prophylactic bilateral salpingo-oophorectomy (PBSO) regarding: (1) their post-operative symptoms, (2) their recollection of pre-operative conversations with their health care providers regarding possible surgical side-effects and (3) what information they would have found helpful to have before surgery. Female BRCA carriers seen through the Yale Cancer Genetic Counseling Program who had PBSO were invited to participate in a questionnaire that assessed their recall of information they received pre-operatively compared with their post-operative knowledge and symptoms related to menopause, cognitive changes, loss of fertility, cancer risks, osteoporosis, heart disease, vasomotor symptoms, urogenital symptoms, sexuality and body image. The questionnaire also elicited written feedback from participants regarding their decision to have PBSO, what they wished they had known before surgery, advice for other BRCA carriers considering this surgery and advice for health care providers who counsel women about PBSO. Two hundred and ninety female BRCA carriers were invited to participate and 113 (39.0%) indicated they were interested. Of those, 99 (87.6%) returned their questionnaire and 98 (86.7%) responses were included in the analysis. The mean age at PBSO was 45.5 years (range: 32–63 years). The five most common “frequent” or “very frequent” post-surgical symptoms were: vaginal dryness (52.1%), changes in interest in sex (50.0%), sleep disturbances (46.7%), changes in sex life (43.9) and hot flashes

(42.9%). The majority of women would have found it helpful to have more information regarding the impact of this surgery on their sex life (59.2%), the availability of sex counseling (57.1%) and the risk of coronary heart disease (57.1%). This study illustrates that while health care providers are discussing selected side effects of PBSO, women undergoing this surgery have other concerns that should be addressed. This information provides insights into the informational needs of BRCA carriers considering PBSO.

**Keywords** Prophylactic bilateral salpingo-oophorectomy · BRCA1 and BRCA2

### Introduction

The hereditary breast and ovarian cancer genes, BRCA1 and BRCA2, were cloned in the early 1990s and clinical testing became available in 1996 [1, 2]. Mutations in these genes account for the majority of autosomal dominant hereditary breast and ovarian cancer families [3].

It has been well established that female mutation carriers have a high lifetime risk of developing ovarian cancer ranging from 15 to 60% [4–6]. Even the lowest end of this range is much greater than the population risk of 1–2% [1]. Ovarian cancer is very difficult to detect at an early, treatable stage (even when using CA-125 and transvaginal ultrasounds) [2]. Therefore, it is recommended that women who carry BRCA mutations consider having their ovaries and fallopian tubes removed by age 35–40 [7, 8]. Recommendations for prophylactic bilateral salpingo-oophorectomy (PBSO) at younger ages may be based on the family history [3].

Several studies have demonstrated the efficacy of PBSO in BRCA mutation carriers [1, 9, 10]. In BRCA carriers

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whose pathology comes back normal, this surgery is highly effective in reducing the subsequent risk of ovarian-type cancer [10]. Therefore, PBSO is clearly indicated for female BRCA carriers by age 40 and is recommended by the National Comprehensive Cancer Network and the American College of Obstetricians and Gynecologists [11, 12].

The uptake of PBSO in BRCA carriers aged 40 or older is >80% [13, 14]. These studies suggest that a significant proportion of women with a BRCA mutation who are eligible for PBSO will pursue surgery.

More attention is now being paid to the impact of this surgery on young pre-menopausal women and the effect on menopausal symptoms, cognitive changes, loss of fertility, cancer risks, osteoporosis, heart disease, vasomotor and urogenital symptoms, sexuality and body image [15, 16]. Compared to screening with annual transvaginal ultrasounds and CA-125 blood marker screens, high-risk women who pursue PBSO report more discomfort, less pleasure and satisfaction during sexual activities and significantly more endocrine symptoms [17].

Some women consider the use of hormone replacement therapy to alleviate menopausal symptoms; however, its use in BRCA carriers is somewhat controversial because of the chance that these hormones may increase the risk for breast cancer [18]. Even those who use hormone replacement therapy (HRT) after PBSO are more likely to report vasomotor symptoms and significantly more sexual discomfort due to vaginal dryness and dyspareunia than those undergoing screening [19]. Therefore, HRT may be not be a cure-all for menopausal symptoms or changes in sexual functioning associated with surgical menopause and may be less effective than is often assumed.

Clearly, PBSO is indicated in female BRCA carriers to reduce their risk of ovarian cancer, which is hard to detect at early stages and is associated with significant 5-year mortality rates (54%) [20]. Although the knowledge of PBSO post-surgical symptoms would not change surgical recommendations, providing women with accurate expectations and options may be important for their long-term adjustment, treatment satisfaction and quality of life.

Few studies have assessed the information being provided to women considering PBSO [21, 22] and no data exist on the unique circumstances of BRCA carriers pursuing this prophylactic surgery. In this report, we present the results of a retrospective questionnaire-based study of BRCA carriers regarding: (1) their post-operative symptoms, (2) their recollection of pre-operative conversations with their health care providers regarding possible surgical side-effects and (3) what information they would have found helpful to have before surgery.

## Methods

### Patient population

Eligible female BRCA1 or BRCA2 mutation carriers who were seen through the Yale Cancer Genetic Counseling Program were contacted by mail with a study invitation letter ( $N = 290$ ). Participants were deemed eligible if they were  $\geq 35$  years old or  $< 35$  and known to have pursued PBSO. Participants were excluded if they had a previous history of ovarian cancer, known cognitive impairment that would interfere with completing the questionnaire, known severe psychiatric co-morbidity or a co-morbid, life-threatening condition with life expectancy of less than 1 year.

Interested participants received an IRB-approved consent form for consideration and questionnaire by mail.

### Questionnaire

The questionnaire consisted of 12 quantitative and 3 open-ended questions. Demographic and medical information included: age at time of prophylactic surgery, timing of prophylactic surgery in relation to learning one's BRCA status (before/after), type of surgery and menstrual status before surgery. A symptom-based checklist assessed the frequency of symptoms after PBSO on a 6-point Likert-type scale from "very frequent" to "never." These were compared to "yes/no" questions about which of the same symptoms were discussed with participants pre-operatively. A second pair of checklists assessed when specific topics relating to cancer risks and PBSO were discussed with the participants (before, after or never) and the amount of information participants would have liked to receive on a particular subject (more/less/the same). In addition, women were given the opportunity to provide written responses to a series of open-ended questions regarding their decision to have PBSO, what they wished they had known before surgery, advice for other BRCA carriers considering this surgery and advice for health care providers who counsel women about PBSO.

### Data analysis

Patient responses were entered into an SPSS database file (version 16.0). A descriptive analysis was undertaken of all study variables to examine distributions, means and standard deviations. Responses to open-ended questions were coded and the frequency of each reported theme was tabulated.

*T*-tests were also performed to determine if a statistically significant difference was found between the groups of

respondents who reported that they were menopausal before surgery compared to those who were pre-menopausal. The analysis included all symptoms listed in Table 2. *P* values of less than 0.05 were considered significant.

**Results**

Characteristics of study population

Two hundred and ninety female BRCA carriers were invited to participate and 113 (39.0%) indicated they were interested. Of those, 99 (87.6%) returned their questionnaire and 98 (86.7%) responses were included in analysis. One response was excluded due to an ovarian cancer diagnosis.

The mean age of PBSO was 45.5 years (SD, 7.41) (range: 32–63 years) and the mean age at the time of study participation was 51.4 years (SD, 8.31) (range: 33–73 years). Eighty-five percent pursued PBSO after learning their BRCA status, 48.0% were premenopausal at the time of surgery, 55.1% had PBSO and 44.9% had TAH-BSO. Respondents discussed which type of surgery to pursue with their gynecologist (71.4%), genetic counselor (70.4%), oncologist (45.9%), gynecological oncologist (30.6%), primary care physician (21.4%) and gynecological nurse (1.0%). None of the respondents (0%) discussed their type of surgery with a gynecological fellow. If making the decision again, 96.9% would pursue the same surgery and 97.9% would recommend PBSO to another female BRCA carrier (Table 1).

Menopausal symptoms

The five most common “frequent” or “very frequent” post-surgical symptoms were: vaginal dryness (52.1%), changes in interest in sex (50.0%), sleep disturbances (46.7%), changes in sex life (43.9%) and hot flashes (42.9%). An analysis of the mean symptom scores revealed that the frequency of these same five symptoms each had a mean score of 3.0 or greater (on a scale from 1 to 6). The least commonly reported symptoms were vaginal itching (7.2%), urinary incontinence (5.1%), weight loss (2.0) and urinary tract infections (1.0%) (Table 2).

When symptoms were analyzed according to participants’ menopausal status prior to surgery, respondents who were having normal periods experienced significantly more hot flashes ( $t = X, P = 0.003$ ) and night sweats ( $t = X, P = 0.002$ ) after PBSO. Urinary tract infections were also more common in this group, although not statistically significant ( $t = X, P = 0.058$ ).

**Table 1** Demographic and medical characteristics of participants

	Percentage
Age at PBSO (mean 45.5, SD 7.41)	
30–35	9.2
36–40	21.4
41–45	18.4
46–50	23.5
51–55	17.3
56–60	9.2
61–65	1.0
When was PBSO	
Before learning BRCA status	13.3
After learning BRCA status	86.7
Menopausal status before PBSO	
Premenopausal	49.0
Peri/menopausal	51.0
Type of surgery	
TAH-BSO	44.9
BSO, only	55.1
Discussed surgery with:	
Gynecologist	71.4
Genetic counselor	70.4
Oncologist	45.9
Gynecological oncologist	30.6
Primary care physician	21.4
Gynecological nurse	1.0
Gynecological fellow	0
No one	0
Pursue same surgery again?	
Yes	96.9
No	3.1
Recommend surgery to another BRCA carrier?	
Yes	97.9
No	2.1

Recall of pre-surgical symptom discussion

When asked which potential symptoms were discussed by their health care provider prior to surgery, respondents reported that these included the possibility of hot flashes (69.4%), night sweats (59.2%) and vaginal dryness (57.1%) were discussed most frequently. The least commonly discussed symptoms were hair thinning, urinary tract infection and weight loss, each reported by 11.2% of respondents. A list of other symptoms discussed by providers is listed in Table 3.

Recall of pre-surgical topic discussion

When asked which topics were discussed with them before surgery almost every respondent reported that the impact of

**Table 2** Reported menopausal symptoms

	Mean	SD	Percentage reporting “frequent” or “very frequent”
Change in interest in sex	3.2	1.8	50.0
Change in sex life	3.2	1.8	43.9
Vaginal dryness	3.2	1.7	52.1
Hot flashes	3.1	1.7	42.9
Sleep disturbances	3.0	1.8	46.9
Night sweats	2.7	1.8	33.7
Painful intercourse	2.7	1.8	31.0
Weight gain	2.5	1.9	40.8
Mood swings	2.2	1.7	23.5
Change in body image	2.2	1.9	31.6
Depression	2.2	1.6	21.4
Hair thinning/loss	1.4	1.7	16.3
Vaginal itching	1.3	1.5	7.2
Urinary incontinence	1	1.4	5.1
Urinary tract infections	0.4	0.9	1.0
Weight loss	0.3	0.8	2.0

**Table 3** Symptoms discussed with participants before surgery

Symptom	Percentage that reported symptom was discussed before surgery
Hot flashes	69.4
Night sweats	59.2
Vaginal dryness	57.1
Sleep disturbances	48
Mood swings	45.9
Change in interest in sex	41.8
Weight gain	39.8
Change in sex life	36.7
Depression	35.7
Painful intercourse	29.6
Urinary incontinence	24.5
Vaginal itching	22.4
Change in body image	21.4
Hair thinning/loss	11.2
Urinary tract infections	11.2
Weight loss	11.2

surgery on their ovarian cancer risks was discussed (99.0%). The majority also reported that the impact of surgery on their breast cancer risks (78.9%), their options for TAH-BSO vs. BSO (75.5%), menopausal status (70.4%), osteoporosis (57.1%) and childbearing ability (54.1%) were discussed before surgery. Fewer respondents reported that the impact of surgery on coronary heart disease (33.7%), sex life (28.6%), body image (16.3%) and the availability of sex counseling (9.2%) were discussed before surgery. However, ~60–80% of patients reported that several

topics were *never* discussed. These included: the availability of sex counseling, impact of surgery on body image, impact of surgery on sex life and impact of surgery on their risks for coronary heart disease (Table 4).

#### Pre-surgical information that would have been helpful

When asked what information they would have found helpful to have before surgery, participants' responses included the impact of surgery on their sex life (59.2%), risk of coronary heart disease (57.1%) and the availability of sex counseling (57.1%). Fewer patients reported needing more information regarding the impact of surgery on breast cancer risks (17.3%), ovarian cancer risks (13.3%) and loss of childbearing ability (1.0%) (Table 5).

#### Open-ended responses

Each of the three open-ended questions were responded to by 33.7, 48 and 34.7% of respondents, respectively. The first question inquired about what respondents wished they had known before surgery. Eleven (33.3%) wished they had known about the impact of surgery on their sex life/libido, 11 (33.3%) commented on menopausal symptoms, 6 (18.2%) focused on the medical aspects of surgery and cancer risks, 3 (9.1%) stated they had sufficient information, 1 (3.0%) wished she had less information and 1 (3.0%) wished she had more information about fertility options.

The second question asked about advice for other BRCA carriers considering this surgery. Twenty-five (53.2%) recommended the surgery and 17 (36.2%) encouraged

**Table 4** When topics were discussed with participants in relation to their surgery

	Discussed before surgery	Never discussed	Discussed after surgery
Impact of surgery on ovarian cancer risks	99.0	0	1.0
Impact of surgery on breast cancer risk	78.6	11.2	2.0
Pros and cons of TAH-BSO vs. BSO	75.5	14.3	1.0
Impact of surgery on menopause	70.4	17.3	2.0
Impact of surgery on osteoporosis	57.1	32.7	8.2
Loss of childbearing ability	54.1	29.6	0
Impact of surgery on coronary heart disease	33.7	60.2	3.1
Impact of surgery on sex life	28.6	61.2	6.1
Impact of surgery on body image	16.3	77.6	2.0
Availability of sex counseling	9.2	81.6	5.1

**Table 5** Topics that would have been helpful to have more information about before surgery

	Percentage of respondents that said it would be helpful to have more info about...
Impact of surgery on sex life	59.2
Availability of sex counseling	57.1
Impact of surgery on coronary heart disease	57.1
Impact of surgery on body image	49.0
Impact of surgery on osteoporosis	43.9
Pros and cons of TAH-BSO vs. BSO	28.6
Impact of surgery on menopause	25.5
Impact of surgery on breast cancer Risk	17.3
Impact of surgery on your ovarian cancer risks	13.3
Loss of childbearing ability	1.0

getting as much information as possible, talking with others and considering the surgery. Five participants (10.6%) focused on sexual side effects, sex counseling and talking with their partner about the sexual side effects.

Thirty-four (34.7%) responded to the third question regarding advice for health care providers talking with women about PBSO. Several responses had multiple themes and were counted more than once. Twenty-three (67.6%) suggested giving patients as much information as possible, particularly about the emotional, menopausal and sexual changes, 10 (29.4%) advised health care providers to be honest, compassionate and patient, 4 (11.8%) suggested that more information should be discussed about the technical aspects of surgery, 4 (11.8%) suggested that providers refer their patients to other resources/programs/genetic counselors/patients for more information, and 2 (5.9%) reported that they had excellent care and had no advice.

### Discussion

Our study has several limitations that should be noted, particularly when counseling women considering PBSO. This was a retrospective questionnaire-based study that relied on the recall of participants. Respondents were, on average, 5.9 years out from PBSO, and this may have impacted their recollection of pre-surgical discussions. No pre-surgical baseline data were available and we had no control group. There may be selection biases, in which women with the greatest number of post-surgical symptoms or concerns were more inclined to participate. It remains possible that the non-responders may have a significantly different experience than those who participated in this study. We did not collect data on the use of hormone replacement therapy, which may have influenced the responses to symptom-based questions.

Despite these limitations, this study provides insights into the informational needs of BRCA carriers considering PBSO. To our knowledge this is the largest assessment of BRCA carriers' symptoms and informational needs before and after PBSO. Observations from this study can help guide health care providers who discuss PBSO with female BRCA carriers.

In this cohort, the symptoms that were discussed most frequently with patients *pre-operatively* were hot flashes, night sweats and vaginal dryness. All three were discussed with >50% of respondents *pre-operatively*. The most commonly reported *post-operative* symptoms included two of the symptoms discussed *pre-operatively*: hot flashes and vaginal dryness. However, three additional symptoms were reported by >40% of respondents *post-operatively*. These included changes in libido, changes in sex life and sleep disturbances. Therefore, it appears that 60% (3/5) of the most commonly experienced symptoms were not discussed with patients *pre-operatively*. This represents a disconnect from what health care providers are anticipating and discussing with their patients versus the symptoms that

patients are actually experiencing. It also suggests that many women received little or no pre-operative discussion regarding the impact of this surgery on their libido, sex life and sleep disturbances; three out of the five most commonly-reported symptoms.

Respondents were asked about their discussion with their providers on general topics in addition to specific symptoms. When asked which topics were discussed *pre-operatively* it appears that most health care providers discussed the impact of PBO on ovarian and breast cancer risk, the pros and cons of the different types of surgery and the impact of surgery on menopause. However, it is striking that ~60–80% of respondents reported that no information was provided about the availability of sex counseling, impact of surgery on body image, impact of surgery on sex life and impact of surgery on their risks for coronary heart disease. These same topics ranked highest when participants were asked which topics they would have liked to have more information about *pre-operatively*. While the focus of prophylactic surgery discussions is often on cancer risk reduction, as it was in this cohort, it appears that significant issues involving sexual side effects after PBO are pushed to the back burner or are ignored.

Some providers may be fearful that patient knowledge of post-surgical side effects would impact patients' decision to pursue PBO. However, in this cohort, and in accordance with previous studies, the vast majority of BRCA carriers who had this surgery would pursue it again [21, 23–25]. Furthermore, almost all respondents in this study would recommend PBO to another BRCA carrier. Therefore, it appears unlikely that a full understanding of the possible post-surgical side effects would change BRCA carriers' decision to pursue PBO. However, patients would benefit from a more accurate depiction of post-surgical side effects in that it would help more accurately shape their expectations. Armed with this knowledge, patients can make better, more informed decisions about the options to manage possible side effects and may feel better prepared and informed post-surgery. The lack of information provided about side effects and available treatments is illustrated by one patient's response to one of the open-ended questions that she wished she was aware of "treatment options for vaginal dryness and sexual interest changes." There appears to be a need for education regarding side effects and the available treatment options.

Patients may also be too shy or embarrassed to discuss these topics with their providers. In an opinion poll that assessed communication between patients and physicians concerning sexual problems 85% of Americans said they would discuss a sexual problem with their health care provider [26]. However, a distressing 71% thought that their provider would dismiss their concerns and 68% said

that it would embarrass their provider. Although this poll queried the general population, BRCA mutation carriers may face similar fears. Some patients may also feel guilty about bringing up surgical side effects because they believe they should feel "lucky" or "thankful" for having the opportunity to "dodge cancer" [27]. One respondent, who experienced significant post-surgical symptoms, stated that at least she'll "have the chance of a full long life." This may be in contrast to other family members who died at an early age from cancer. Another commented that her provider was so focused on her "being cancer free" that they didn't discuss any issues that might arise after surgery. While these women do feel fortunate, they should also have had the opportunity to have their concerns and symptoms addressed.

One way to include this topic is to incorporate relationship status and sexual health history as part of each patient's medical history or intake. Many health professions already have a battery of health related questions they ask every patient and are often tailored based on the healthcare provider's sub-specialty. The addition of several body image and sexuality questions could be added to this interview and are critical aspects of treating the entire patient. By bringing up the topic before surgery this process can begin gradually. One respondent put it succinctly that providers should "look at the female as a whole- not just the surgical procedure." Beginning the conversation also lets the patient know that this is a topic they can bring up again, if they wish. One respondent took it a step further stating that "providers need to do more to keep the door open." Another urged providers "not to assume [that patients] know the questions to ask." Ultimately, it is the responsibility of the health care provider to provide patients with an understanding of possible post-surgical side effects, check in with them about their symptoms over time and provide treatment options or referrals to address their side-effects.

While we appreciate that discussions can not completely shift to include new topics at the expense of other relevant medical information, it is possible that the scope and depth of preoperative conversations needs to be widened. PBO is clearly the right medical decision for many women who carry BRCA mutations; however, they would benefit from a more accurate depiction of possible post-surgical side effects. Health care professionals counseling women with BRCA mutations need to be proactive in discussing sexual topics, explain their reasons for asking quality of life questions, educate patients, provide resources and keep the lines of communication open. By starting these conversations, health care providers can create a comfortable environment for patients to talk about their side-effects, ultimately discuss treatment options with their providers and improve their quality of life.



## Conclusion

Although the risk:benefit ratio clearly favors PBSO for most BRCA carriers by age 40, the pre-surgical conversations with healthcare providers should include a balanced discussion of the physical and emotional changes that may follow this surgery. The impact of PBSO on libido, sexual functioning and the consequences for bone and heart health should be included in this dialogue. Information regarding how to manage menopausal side-effects, as well as pre- and post-surgical sexual rehabilitation counseling, should be available to patients and their partners. Although PBSO is highly-effective in reducing cancer risk in female BRCA carriers, the effects of these choices on sexual functioning should not be underestimated.

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