

Risk-Reducing Bilateral Salpingo-Oophorectomy and Sexual Health: A Qualitative Study

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Abstract

Objective: To examine the impact of risk-reducing bilateral salpingo-oophorectomy (RRBSO) on sexual function in BRCA gene mutation carriers, compared with the effect on women undergoing BSO (bilateral salpingo-oophorectomy) for benign indications from a qualitative perspective.

Methods: Our study included 25 women who had undergone either a RRBSO because of BRCA carrier status or a BSO for a benign gynaecologic indication. Women were invited to participate if they were at least six months post-BSO. They took part in an individual, private interview during which they were asked open-ended questions about their sexual health in the context of undergoing BSO. They also completed self-report measures of sexual response, sexual distress, sexual self-image, and mood.

Results: Using content analysis of interviews, saturation in themes was reached after 15 interviews and four main themes were identified: (1) preoperative knowledge of sexual side effects, (2) preoperative drive to educate oneself on BSO side effects, (3) partner support, and (4) treatment for sexual side effects. Preoperative awareness of post-BSO sexual side effects was highly correlated with patient satisfaction and inversely correlated with postoperative sexual distress. A majority of participants reported that they did not discuss post-BSO sexual functioning with their physicians, and had to seek out information independently. Satisfaction with RRBSO remained high regardless of whether or not participants reported post-BSO sexual distress. Self-report questionnaires did not reveal any differences between the two groups on measures of sexual function.

Conclusion: This study provided a nuanced view of sexual health in women following RRBSO that was not captured by self-report questionnaires. Women with preoperative knowledge of post-BSO sexual side effects report being more prepared for surgery, and experience less sexual distress following their BSO.

Key Words: Oophorectomy, risk-reducing bilateral salpingo-oophorectomy, sexual health, sexual response, qualitative research

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Résumé

Objectif : Examiner les effets de la salpingo-ovariectomie bilatérale visant la réduction du risque (SOBRR) sur la fonction sexuelle chez les porteuses de la mutation du gène BRCA, par comparaison avec les effets qui s'exercent sur les femmes qui subissent une SOB (salpingo-ovariectomie bilatérale) en raison d'indications bénignes, d'un point de vue qualitatif.

Méthodes : Notre étude portait sur 25 femmes qui avaient subi une SOBRR en raison de leur statut de porteuse de la mutation du gène BRCA ou une SOB en raison d'une indication gynécologique bénigne. Les femmes ont été invitées à participer à l'étude si leur SOB remontait à au moins six mois. Elles ont pris part à une entrevue individuelle privée au cours de laquelle nous leur avons posé des questions ouvertes au sujet de leur santé sexuelle dans le contexte de l'intervention de SOB subie. Elles ont également rempli des mesures d'auto-évaluation de la réaction sexuelle, de la détresse sexuelle, de l'image de soi du point de vue sexuel et de l'humeur.

Résultats : Au moyen de l'analyse du contenu des entrevues, une saturation des thèmes a été atteinte après 15 entrevues et quatre thèmes principaux ont été identifiés : (1) connaissance préopératoire des effets sexuels indésirables; (2) volonté préopératoire de se renseigner sur les effets indésirables de la SOB; (3) soutien du partenaire; et (4) traitement visant les effets sexuels indésirables. La connaissance préopératoire des effets sexuels indésirables associés à la SOB était en forte corrélation avec la satisfaction de la patiente et présentait une corrélation inverse avec la détresse sexuelle postopératoire. Une majorité de participantes ont signalé ne pas avoir discuté de la fonction sexuelle post-SOB avec leurs médecins; elles ont dû obtenir des renseignements de façon indépendante. Le niveau de satisfaction envers la SOBRR est demeuré élevé, peu importe si les participantes ont signalé une détresse sexuelle post-SOB ou non. Les questionnaires d'auto-évaluation n'ont révélé aucune différence entre les groupes en ce qui concerne les mesures de la fonction sexuelle.

Conclusion : Cette étude a fourni une vue nuancée de la santé sexuelle des femmes à la suite de la SOBRR que les questionnaires d'auto-évaluation n'ont pas permis de mettre au jour. Les femmes qui disposent de connaissances préopératoires au sujet des effets sexuels indésirables de la SOB signalent qu'elles sont mieux préparées à subir la chirurgie et qu'elles subissent moins de détresse sexuelle à la suite de celle-ci.

INTRODUCTION

Women with mutations in BRCA1 or BRCA2 genes are at increased risk for the development of ovarian cancer.^{1,2} Bilateral salpingo-oophorectomy significantly reduces the risk of ovarian cancer in women who are BRCA carriers^{3,4} and improves both overall and cancer-specific mortality.⁵ Both premenopausal and postmenopausal BRCA carriers may choose a RRBSO as the most effective measure to try to prevent the development of ovarian cancer. RRBSO has also been shown to reduce cancer-related anxiety and to be associated with a high level of patient satisfaction.^{6,7} When completed prior to menopause, BSO also reduces breast cancer risk in BRCA-positive women.

Most studies suggest that gynaecologic surgery is not associated with impaired sexual function or sexual distress, but other studies, particularly those concerning gynaecologic cancer, suggest a negative impact on sexual function.⁸⁻¹¹ There is a growing body of evidence to suggest that RRBSO for BRCA carriers affects sexual response,^{7,12-15} and hormone therapy appears to have limited benefit in alleviating sexual symptoms from surgical menopause in BRCA carriers.^{15,16} In particular, in a recent prospective trial, 114 women who underwent RRBSO experienced a significant decline in sexual desire and pleasure, and this was only minimally attenuated with hormone therapy.¹⁵ Postoperative levels of sexual function in this group of premenopausal women were comparable to those of postmenopausal women. Moreover, among those women with potentially hormone-sensitive cancers, hormone therapy is often not an option. As concerns about long-term sexual functioning may affect women's decision-making when considering BSO for cancer risk reduction, it is important to understand the extent to which BRCA status and subsequent RRBSO predict negative sexual sequelae compared with BSO for a benign gynaecologic condition. Thus, the aim of this study was to use qualitative analysis of women's narratives

to explore sexual function in BRCA carriers who had a RRBSO compared with sexual function in women undergoing BSO for benign indications. Prospective trials comparing sexual sequelae before and after RRBSO have been carried out,¹⁵ and these document the new onset of sexual problems following RRBSO. However, women's own experiences of these changes, particularly in light of the relief experienced from reducing the risk of cancer, have never been explored. Qualitative methods offer a depth of analysis that is ideally suited to explore such nuance, particularly with respect to sexuality.¹⁷

METHODS

Our initial sample consisted of 39 women who had undergone BSO at least six months earlier, and 25 of these women agreed to take part in a detailed personal interview. Here we report on the findings from the first 15 interviews conducted, given that saturation (i.e., no new themes emerging from analysis of the entire group) was reached at this point. This included 11 women who had RRBSO because they were a carrier of a BRCA 1/2 gene mutation (group 1), and four women who had BSO for a benign gynaecologic indication (group 2). Women in group 1 were identified through the hereditary cancer program at our affiliated cancer centre as having undergone risk-reducing surgery. Women in group 2 were identified through a database of surgery patients maintained by our gynaecologic oncology collaborators. Women with a history of any kind of cancer or pelvic radiation were excluded.

There were no significant differences on any demographic or self-report questionnaire endpoint between the 15 women whose interviews were qualitatively analyzed and the 10 women who consented to participate but for whom interviews were not analyzed.

Following chart review, potential participants in both groups were sent a letter inviting them to participate. Interested women then contacted the study coordinator, who arranged for them to complete a package of questionnaires at their home. Instructions were given to complete the questionnaires in reference to the past two months of their sexual experiences, not in reference to their history of sexual functioning pre-surgery. They were then informed about a follow-up interview during which they would be asked about their experiences of sexual health in the context of their BSO. Key questions about the impact of BSO on their sexuality, whether they discussed sexuality with their surgeon prior to the BSO, and how much information they sought on their own, was discussed in an

ABBREVIATIONS

BDI	Beck Depression Inventory
BISCS	Body Image Self-Consciousness Scale
BSO	bilateral salpingo-oophorectomy
FSDS	Female Sexual Distress Scale
FSFI	Female Sexual Function Index
HT	postmenopausal hormone therapy
RRBSO	risk-reducing bilateral salpingo-oophorectomy
STAI	State-Trait Anxiety Inventory

open-ended manner by a masters-level clinical counsellor with training in women's health. Following completion of the study, women were provided a \$20 honorarium. All women provided informed consent.

The overall goal was to explore how women experienced the impact of BSO on their sexual health, and to gather information about what factors might have contributed to their post-surgery sexual experiences. The first three authors, none of whom were directly involved in carrying out the interviews, used the typical analytic framework for qualitative studies described by Marshall and Rossman.¹⁸ The investigators initially read the interviews independently and made general impression notes in the margins of the transcript copies. A first meeting of the investigators then took place where they discussed initial reactions and formulated a tentative list of themes. With these broad themes in mind, the investigators then re-read each of the transcripts and meticulously coded all passages of text that directly corresponded to the initial list of themes. Investigators also continued to be attentive to themes that were not apparent upon the first read-through and made note of these additional themes for more exploration. A second meeting that allowed investigators to consolidate their work and resolve any discrepancies resulted in a list of five major themes. The investigators then performed a third read-through of the transcripts, during which they divided the themes, and selected representative passages of text supporting those themes.

To supplement sexual health information from the interviews, we also administered some validated self-report measures of sexual response, sexual distress, sexual self-image, mood, anxiety, and relationship adjustment. Sexual response was measured with the Female Sexual Function Index,¹⁹ a 19-item measure of desire, arousal, lubrication, orgasm, pain, and sexual satisfaction, which has been validated in women with and without a sexual dysfunction. The Female Sexual Distress Scale²⁰ was used to measure sex-related distress; it is a 12-item measure with good discriminant validity, internal consistency, and test-retest reliability. Sexual self-image was assessed with the Body Image Self-Consciousness Scale.²¹ The BISCS is a 15-item self-report measure of self-consciousness about one's body during physical intimacy with a partner. The BISCS has been shown to be highly internally consistent (Cronbach alpha range = 0.94 to 0.97) and to have high test-retest reliability ($r=0.92$) over a three-week period. Convergent and divergent validity for the scale have also been demonstrated, with the BISCS predicting sexual experience and sexual esteem beyond effects of actual body size and other measures of general body image.²¹ We also administered the Beck

Depression Inventory²² as an indicator of general mood, and the State-Trait Anxiety Inventory as a general measure of state and trait anxiety.²³ Because of the small sample size, these questionnaires provided only a descriptive view of our sample, and we did not carry out between-group analyses or significance testing.

All procedures were approved by the British Columbia Cancer Agency Ethics Review Board.

RESULTS

Not unexpectedly, the average age (\pm SD) for group 1 (49.1 years \pm 8.0) was lower than group 2 (54.8 \pm 6.7). The RRBSO group were slightly older in their age of sexual debut (18.4 years \pm 4.2) compared with group 2 (16.5 \pm 2.4) and also were less frequently orgasmic than women in group 2 (45% vs. 65%). All women, except for one Asian woman in the RRBSO group, were of Euro-Canadian descent. Seven of the 15 women had some post-secondary education and 10 of 15 were currently employed. Five of the 15 women were currently receiving HT (four in group 1 and 1 in group 2). Although five of the 15 women reported being dissatisfied with the level of sexual closeness in their relationship, none of the women had ever previously sought sexual health counselling.

Although 25 women agreed to participate and were interviewed, we reached saturation in themes after 15 interviews were analyzed. Thus, our results are focused on those 15 analyses. Eleven of the interviews were carried out with BRCA carriers who underwent RRBSO (group 1), and four with women who had surgery for benign reasons (group 2). Four major themes were identified from our analysis of the transcripts: (1) preoperative knowledge of sexual side effects, (2) preoperative drive to educate self on BSO after effects, (3) partner support, and (4) treatment for sexual side effects.

Theme 1: Preoperative knowledge of sexual side effects

Of the 15 participants, six anticipated some impact on sexual function (four were from group 1). The anticipated side effects included decreased sexual desire, impaired lubrication, inability to experience orgasm, and dyspareunia. These women obtained their preoperative information from various resources such as the Internet, books, support groups, and (most commonly) friends who had similar surgical procedures, but not from physicians or other health care providers. Interestingly, among those women who had expected sexual side effects, none reported having any such side effects after their BSO. In addition, they all stated that they felt adequately prepared for surgery.

On the other hand, nine women did not anticipate any sexual side effects of surgery (seven were from group 1), and all reported having sexual side effects after their BSO; this did not appear to depend on whether the BSO was risk-reducing or indicated for a benign condition. These women reported such effects as decreased spontaneous and responsive desire, arousal, ability to orgasm, and increased genital pain. Most of these women reported notable distress as a result of their sexual symptoms. They described themselves as not being adequately prepared for surgery and its effects, and noted that they would have liked more information from their physicians about what to expect after surgery or to be linked to support groups. A participant stated that “no one ever said that you would be having these feelings and sexual discomfort. I don’t think it would have changed my mind, but at least I would have been more informed” [age 59, BRCA-positive group 1].

Despite the occurrence of sexual sequelae, the majority of women (14/15) expressed no regrets about undergoing the surgery. A younger BRCA carrier expressed ambivalence about whether or not she would have undergone the surgery again due to the sexual side effects she was experiencing:

This whole cancer thing is such a scary business. Are the sacrifices I’m making today, are they worth being here for my family and my husband and having a life? I think probably yes . . . I made the right choice. I do have regrets. And if I had to make that decision over again, I don’t know. I don’t think I can say 100% [that] I wouldn’t have gone through with it. It’s a big decision, it really is. [age 44, BRCA-positive group 1]

Several women noted that they would advise other women contemplating BSO to do extensive preoperative research and ask physicians questions on what to expect after surgery. They also stated that they would encourage other women to proceed with the surgery but to be prepared to expect changes to their sexual health.

[R]eally weigh out what your life is now, and make sure you think clearly about what you’re going to encounter after the surgery, to be very realistic about your expectations . . . we went through a lot . . . you just feel so empty . . . your sexuality is gone, and you can go through a hard time. [age 44, BRCA-positive group 1]

Theme 2: Preoperative drive to educate self on BSO after-effects

Some women in our sample actively researched surgical after effects prior to their BSO. Only a few of these

found sufficient literature on sexual functioning. Of the remaining women who actively sought information pre-surgery, they either found only minimal useful information or none at all regarding sexual side effects and BSO.

The few women who did find information on sexual functioning during their research subsequently reported feeling adequately prepared for surgery and its effects. Those who found minimal or no information online on the whole described themselves as being inadequately prepared.

Women also described other personal barriers to seeking preoperative knowledge on sexual side effects such as embarrassment over the sensitive subject nature, inadequate computer skills, being unaware of the appropriate questions to ask and where to direct their questions, and lacking any preconceptions regarding possible changes in sexual functioning. As for external barriers, sexual health was not a subject commonly broached by surgeons or general practitioners, in that most of the participants stated their doctor did not discuss potential sexual side effects.

Theme 3: Partner support

Women unanimously reported that their partners were very supportive of their decision to have surgery, noting that their partners respected women’s decisions to have RRBSO as a personal choice. However, women also shared stories of unsupportive partners regarding onset of the women’s new sexual problems. Among those women who described their partnerships as quite sexual prior to surgery, there was a notable negative effect of their sexual problems on their relationship after the surgery. In addition, these women shared that their partners had made unsupportive actions or comments regarding these changes:

We’ve talked about this and what happens, but he’ll still say “What’s wrong with you,” “How come you don’t do this,” and I’m saying it just doesn’t happen, get it through your head, it’s not you, it’s me [age 44, BRCA-positive group 1].

Only one woman said that her relationship was only slightly affected, and in such a way that was not distressing to her. The remaining women who reported sexual impairments denied that these difficulties affected their relationship. They attributed the minimal impact on their relationship to the fact that they were not very sexually active prior to surgery.

Approximately one half of the women stated that they had warned their partners about the possibility of negative consequences following their BSO. Among this group, most noted that communication helped to elicit partner

Responses to measures of sexual response (FSFI), sexual distress (FSDS), sexual self-image (BISCS), mood (BDI), and state and trait anxiety (STAI) in women who received risk-reducing BSO and women who received BSO because of benign conditions

Variable	Group 1	Group 2
	RRBSO, n = 11 Mean (SD)	Benign BSO, n = 4 Mean (SD)
FSFI-desire	2.01 (1.05)	3.15 (1.84)
FSFI-arousal	4.23 (1.84)	4.00 (1.65)
FSFI-lubrication	4.60 (1.63)	3.80 (1.39)
FSFI-orgasm	4.00 (1.94)	4.00 (2.43)
FSFI-satisfaction	4.10 (1.68)	4.67 (0.92)
FSFI-pain	4.55 (1.61)	5.87 (0.23)
FSFI total score	23.79 (6.89)	26.13 (6.00)
FSDS	14.55 (16.17)	9.25 (8.06)
BISCS	20.55 (21.86)	26.25 (18.08)
BDI	9.18 (8.56)	11.50 (4.12)
STAI-T	33.82 (13.11)	46.00 (10.98)
STAI-S	29.55 (12.89)	40.50 (15.00)

support, whereas a few felt that their partners were uninterested in the topic:

I read him parts of the book I was reading and said this was going to happen and this was going to happen, and he just went “yeah, yeah, yeah.” The reality and the theory did not go hand in hand. Probably if I just asked him right now, “was it worth it?” he would say “of course, to save your life,” but when he bugs me about having sex more often and all the rest of it, I just think he’s not listening. [age 52, BRCA-positive group 1]

There was also the sentiment that preparing one’s partner for sexual changes to come was important.

Theme 4: Treatment for sexual side effects

Less than one half of the women were given HT to treat or prevent sex-related and menopause-associated symptoms following BSO, and the majority of those treated were BRCA carriers. Among this subgroup of hormone users, most of whom were younger than the non-HT users, several stated they were concerned about potential cancer risks of HT. One of these participants stated

[E]veryone was advocating hormone replacement, and I know in the media that hormone replacement was getting such negative press, and it’s viewed as an almost scary alternative, but my surgeons were pretty adamant that I give it a try. They were so concerned about quality of life. So,

I took their advice, with some trepidation, but from the moment I came out of surgery and popped the pill and put on the patch I actually felt pretty great. [age 45, BRCA-positive group 1]

Quantitative Results

The data from the validated questionnaire measures are shown in the Table. Scores on the desire domain of the FSFI were in the range comparable to women with a diagnosis of hypoactive sexual desire disorder,²⁴ whereas scores on the other domains of sexual function were in the normative range. Moreover, the total sexual function score for the RRBSO group (23.8 ± 6.9) fell below the clinical cut-off of 26 for women with sexual dysfunction,²⁴ and the total sexual function score for women in the benign BSO group was just above this clinical cut-off (26.1 ± 6.0).

Scores on the FSDS measure of sexual distress (group 1: 14.5 ± 16.2 ; group 2: 9.3 ± 8.1) suggested that women in the RRBSO group just met the clinical cut-off score²⁰ for significant sex-related distress, whereas women in the benign group did not. Among the six women from the total sample who met the clinical cut-off score of 15,²⁰ four were from the RRBSO group, and two were from the benign BSO group. When we later explored in more detail the narrative stories of those women who met the clinical cut-off for distress, they tended to complain more about difficulties with sexual desire than problems in the other domains of sexual functioning. In addition, women who described the most distress resulting from their lowered sexual desire tended to be younger than women who complained exclusively of genital arousal complaints. Although a regression analysis was not undertaken because of inadequate sample size, exploration of the narratives of those women with high FSDS scores suggested that they tended to be women who had some sexual difficulties prior to surgery and were also more likely to be from the RRBSO group.

Women’s level of body image self-consciousness (20.5 and 26.3, respectively, for groups 1 and 2) suggested that our sample was not overly self-conscious about their body image when with an intimate partner.²¹ Moreover, women in the RRBSO group had even less body image self-consciousness concerns than women in the benign group. In addition, there were no themes related to body image self-consciousness during women’s narrative stories. Thus, it appears that the sex-related distress was not mediated by poor body image.

Mean depression scores, according to the BDI, fell in the non-clinical range for all women; however, three women had scores that fell in the moderately depressed range

(BDI > 30), and two of these women were in the RRBSO group. Scores on state and trait anxiety were somewhat higher in the benign BSO group, but both groups fell in the range comparable with female college norms.

DISCUSSION

The primary aim of our study was to explore the narrative stories of sexual experience among women undergoing RRBSO and women who had BSO for benign indications. Previous studies suggest that while benign gynaecologic surgery is not associated with sexual distress, gynaecologic surgery for malignancy does negatively affect sexual function.^{8–15} In particular, recent prospective studies show a detrimental effect of RRBSO on several domains of sexual function.¹⁵ Therefore, we had anticipated that women who carried a BRCA mutation would have experienced more sexual distress than those who had surgery for benign reasons. This finding was borne out in both the quantitative results and within women's stories. Also, compared with women in the benign BSO group, women who reported the most sex-related distress were from the RRBSO group. Moreover, both the qualitative interviews and the FSFI showed women in the RRBSO group to have more problems in the domain of sexual desire. A potential mediator of this effect is age, as women who expressed more distress over their reduced sexual desire tended to be younger, and women in the BRCA group were younger overall than those in the control group. Furthermore, women's stories suggested that the most important predictor of post-BSO sexual distress was having sexual difficulties prior to surgery.

One of the main themes of our study was the importance of preoperative knowledge regarding post-BSO sexual distress. The women who anticipated sexual side effects after surgery all reported feeling adequately prepared for surgery, and, interestingly, denied any postoperative distress. In direct contrast, the women who had not anticipated any sexual side effects all described post-BSO sexual distress, and did not feel prepared for surgery. These women stated that they would have liked more preoperative information, as this may have helped them to cope with their symptoms better. It appears that preoperative awareness of post-BSO sexual side effects enhanced women's sense of preparedness and may have also attenuated their perceptions of side effects.^{25,26}

Given the importance of preoperative knowledge, we believe that it is imperative for patients to be counselled appropriately by medical personnel regarding sexual health post-BSO. The majority of women in our study had to seek out information independently from friends,

books, the Internet, and support groups. They denied receiving information from their physicians. Counselling from physicians would have been especially beneficial for women who either did not anticipate sexual side effects, or who encountered barriers to accessing information. There is evidence that early physician–patient dialogue about sexual health has a direct relationship with, and can offset, long-term sexual sequelae in cancer survivors.²⁷ It appears that sexual health information is an important component missing from preoperative BSO counselling, and it needs to be better addressed by health care personnel.^{13,14}

Regardless of whether they experienced post-BSO sexual distress, the vast majority of women stated that they had no regrets following the surgery. This is in keeping with previous studies^{6–7,15} that demonstrated that women report a high level of satisfaction with their decision to undergo RRBSO, despite sexual or vasomotor side effects. Furthermore, the majority of participants in our study would recommend the surgery to other BRCA carriers.

This is the first study to use both quantitative and qualitative measures to examine women's sexual function after prophylactic BSO. The main limitation of this study was the relatively small sample size, although for qualitative analyses it is notable that a saturation in themes was reached with 15 women. It is also notable that major themes were not found to differ between the two groups of women. Importantly, qualitative analysis offers a unique view of sexual health in a manner that is not captured by traditional quantitative means¹⁷; thus, the findings from this study are novel and important.

CONCLUSION

Our in-depth analysis of women's stories suggests that RRBSO leads to impairments in sexual desire which are perceived as quite distressing to women. Despite this, women report a high level of satisfaction with RRBSO regardless of postoperative sexual symptoms. Preoperative knowledge of sexual symptoms is strongly correlated with patient preparedness and post-BSO coping. Given the importance of preoperative information, we recommend that medical personnel discuss post-BSO sexual health with their patients prior to surgery.

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