
Article:
Hickey, I., Jha, S. orcid.org/0000-0002-4519-6903 and Wyld, L. orcid.org/0000-0002-4046-5940 (2021) The psychosexual effects of risk-reducing bilateral salpingo-oophorectomy in female BRCA1/2 mutation carriers : a systematic review of qualitative studies. Gynecologic Oncology, 160 (3). pp. 763-770. ISSN 0090-8258

https://doi.org/10.1016/j.ygyno.2020.12.001

Title: The psychosexual effects of risk reducing bilateral salpingo-oophorectomy in female *BRCA1/2* mutation carriers: A systematic review.

Authors: India Hickey[1], Swati Jha[2] and Lynda Wyld[3].

Author Affiliations:

1. University of Sheffield, Department of Oncology and Metabolism, Academic Unit of Reproductive and Developmental Medicine
2. Sheffield Teaching Hospitals NHS Foundation Trust, Jessop Hospital for Women, Sheffield
3. Department of Oncology and Metabolism, University of Sheffield, Sheffield, UK, S10 2RX and Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust, Armthorpe Road, Doncaster.

Corresponding author:

India Hickey, MSc

Sheffield Teaching Hospitals NHS Foundation Trust

Jessop Wing, Tree Root Walk, S10 2SF

Email: india.hickey@hotmail.com

Disclosure of Interests: None

Details of ethics approval: NA

Funding: NA

Abstract

Introduction:

There are 7400 diagnoses of ovarian cancer each year in the UK, causing 4100 deaths. It is estimated that up to 20% of these cases have an inherited genetic aetiology. The most common genetic mutation occurs in the BRCA1 or 2 genes. For women with mutations in these genes, or a high incidence of breast and/or ovarian cancer in their family, risk-reducing bilateral salpingo-oophorectomy (RRBSO) may be offered to reduce the risk of primary ovarian cancer. In premenopausal women this results in immediate onset of surgical menopause. Women experience menopausal symptoms including hot flushes, vaginal dryness, loss of libido and dyspareunia. This article sought to explore the psychosexual impacts of risk reducing bilateral salpingo oophorectomy in the published qualitative literature.

Methods:

PubMed, Medline, Web of Science and PsycInfo were searched for qualitative papers that looked at the impact on RRBSO on individuals who were pre-menopausal at the time of surgery. Studies were quality assessed and data was extracted. Thematic synthesis of the results was performed.

Results:

Of 143 papers identified in searching, 5 qualitative papers were identified relating to interviews with 115 women after RRBSO published between 2000 and 2020. The quality of the papers was moderate. Five different themes were identified related to individual experiences with RRBSO; (1) information needs, (2) psychological impact, (3) psychosexual impact, (4) partner support and (5) hormone replacement therapy (HRT). Women felt underprepared for the impact of the surgery and felt that their information needs were not sufficiently met. The psychological impact of the surgery was generally positive with women expressing a sense of relief after taking control of their cancer risk. The psychosexual impact was more negative and

many women experienced difficulty with the changes they encountered post-surgery which lead to dissatisfaction with their sexual relationships. Partner support was varied and women often felt supported pre-surgery but then expressed frustration as their partners could not understand why their sex life had changed following the surgery. For some women HRT was able to significantly reduce the negative impact of the surgery. Other women were unable to take HRT due to side effects or their perceived risk of breast cancer and so they felt that the surgery had a hugely negative impact on their life.

Conclusion:

Individual experiences of RRBSO were varied and influenced by multiple factors but psychosexual problems were common, often caused significant distress to the women and their partners and were often poorly explained before surgery. There is a need for better counselling both pre- and post-surgery to ensure that women are aware of the side-effects of the surgery and how to mitigate and manage them.

Keywords

BRCA 1, BRCA 2, risk-reducing bilateral salpingo-oophorectomy, sexual function, psychological impact, surgical menopause, hormone replacement therapy, partner support.

Introduction

Ovarian cancer accounts for approximately 4% of all diagnosed cancers in UK females and is responsible for 152,000 deaths across the world each year and 4100 per year in the UK (1,2). It is estimated that up to 20% of these cancers have a hereditary genetic aetiology (3). For these individuals, germline mutations in specific DNA repair genes, mean that the increase in lifetime risk of ovarian cancer can be up to 50% (4) and for breast cancer up to 85%. The most common germline mutations linked to ovarian cancer are the *BRCA1* and *BRCA2* genes, which are involved in homologous DNA recombination, a specialised form of DNA repair (4). Women with *BRCA1/2* mutations are likely to be diagnosed with ovarian cancer 10 years before the average age of diagnosis for sporadic ovarian cancer (4). Breast cancer is similarly diagnosed some 10 years earlier than in sporadic cases.

As screening for early ovarian cancer is ineffective, many women are diagnosed with late stage cancer (5). The five-year survival rate of individuals with late stage ovarian cancer is much lower than early stage diagnosis: 90% for stage I compared to 5% for stage IV (6). For individuals with a genetic predisposition to ovarian cancer, prophylactic surgery is an effective option (7). Risk reducing bilateral salpingo-oophorectomy (RRBSO), which involves the removal of the ovaries and fallopian tubes, results in an 80-95% reduction in ovarian cancer in these high-risk women (8) and reduces the risk of breast cancer in premenopausal women by up to 50% (9). The removal of the ovaries induces premature menopause in pre-menopausal women, which often causes significant side-effects (8).

RRBSO is currently recommended to women with *BRCA1/2* mutations as early as possible after childbearing is complete, although in most cases not before the age of 35-40 to reduce the impact of premature menopause (10). Currently, approximately 50% of women with *BRCA1/2* mutations choose to have RRBSO (11) which is highly effective in reducing the risk of both ovarian cancer development and death. Two of the largest studies of the risk reduction impact of BSO, including over 5000 women, found the hazard ratio for ovarian cancer

development was reduced to between 0.19 and 0.20 (12, 13) and the hazard ratio for overall survival was reduced to between 0.23 and 0.32 (12, 13).

Removal of the ovaries leads to surgically induced menopause (11). For premenopausal women this results in the cessation of menstrual periods and loss of fertility (14). The ovaries normally serve to regulate the menstrual cycle and other bodily functions by secreting oestrogen from the granulosa cells (15). Oestrogen has a wide variety of functions in the body including regulating the menstrual cycle, influencing mood and libido and contributing to bone health (16, 17, 18). HRT is offered to premenopausal women to alleviate the symptoms of oestrogen deficiency after the surgery (19).

Most of the gynaecological symptoms experienced after RRBSO can be attributed to genitourinary syndrome of menopause (GSM). GSM is associated with the loss of circulating oestrogen after surgery and results in various changes to the vagina (20).

The vagina has a high concentration of oestrogen receptors which, when activated by oestrogen, alters cell proliferation and maturation (21). A decrease in circulating oestrogen results in thinning of the vaginal epithelium, altered smooth muscle function, fewer blood vessels and a loss of elasticity (22). The thinning of the epithelium and reduced proliferation leads to atrophy of the vagina (22). There is also a decrease in lubrication leading to vaginal dryness (21). In a study of vaginal atrophy, women reported that vaginal dryness was the most bothersome symptom (23). Lubricants may be used for short-term relief and for women who cannot have hormone-based therapy due to cancer risk (20).

Dyspareunia (pain on intercourse) is also a result of decreased oestrogen (21). Decreased density of connective tissue in the vagina due to a decrease in oestrogen results in a loss of elasticity (21). The lack of elasticity combined with a lack of lubrication and a thin epithelium makes intercourse painful for many post-menopausal women (24). Finch and colleagues (25) studied the effects of RRBSO on premenopausal women, reporting a significant decrease in sexual pleasure (associated with dyspareunia) after RRBSO.

Oophorectomy may also influence mood. A study by Rocca and colleagues (26), found a higher incidence of depression in women who had a premenopausal RRBSO. Another study looking at women who were premenopausal at the time of RRBSO found there was a significant decrease in depression score one month after beginning HRT and the anxiety score dropped two months later (27). There is also a notable reduction in libido following RRBSO (28).

Therefore women who undergo RRBSO may suffer a range of gynaecological and psychological consequences from their surgery many of which impact on their sexuality.

While many studies have attempted to understand what happens to an individual who experiences surgically induced menopause there is little published about the psychosexual impacts. The aim of this systematic review was to determine the psychosexual and psychological impact of risk-reducing bilateral salpingo-oophorectomy in female BRCA1/2 mutation carriers from a patients' perspective by focusing on qualitative studies.

Methods

Search strategy

A systematic search of PubMed, Medline, Web of Science and PsycInfo was performed. The search terms used included 'risk-reducing bilateral salpingo-oophorectomy', 'sexual impact', 'psychological impact', 'psychosexual impact' and 'BRCA'. Databases were searched from April 1996 to April 2020 to identify published peer-reviewed articles. The databases were chosen as they covered both medical and psychological studies. The reference lists of relevant papers were hand searched and a database search for publications citing relevant papers was also conducted. Abstract screening was performed to identify studies that matched the inclusion criteria (Table 2) followed by full text screened.

Inclusion criteria	**Exclusion criteria**
Primary research only	
Qualitative research (mixed-method studies allowed if qualitative data was reported separately)	
Articles available in English	
Women who had risk-reducing bilateral salpingo-oophorectomy	Only women who were waiting to have the surgery or had chosen surveillance only
Women were confirmed BRCA mutation carriers or had a family history of ovarian cancer	Other genetic conditions that predispose an individual to ovarian cancer e.g. Lynch Syndrome
Data was included about women who were premenopausal at the time of surgery	Only data about postmenopausal women

Table 2. Inclusion and exclusion criteria for literature search

Quality appraisal

All qualitative papers used interviews as their primary form of data collection, making methodological comparison easier. The mixed methods appraisal tool (MMAT) (29) was used to decide whether qualitative studies should be included based on their methodology. No studies were excluded due to poor methodology. The Standards for Reporting Qualitative Research (SQRQ) checklist (30) was used to assess the reporting quality of the qualitative papers.

Data extraction

A data extraction form from the National Collaborating Centre for Mental Health (31) was modified to fit the current study (see supplemental materials 1). The form was used to extract information about study design, participants, methodology and results.

Results

Study selection

143 studies were identified through database searches and hand searching citation lists. Studies were first screened by title and then by abstract. Full-text screening was carried out for ten studies and five studies were deemed appropriate for analysis, see Figure 2 for PRISMA flow diagram.

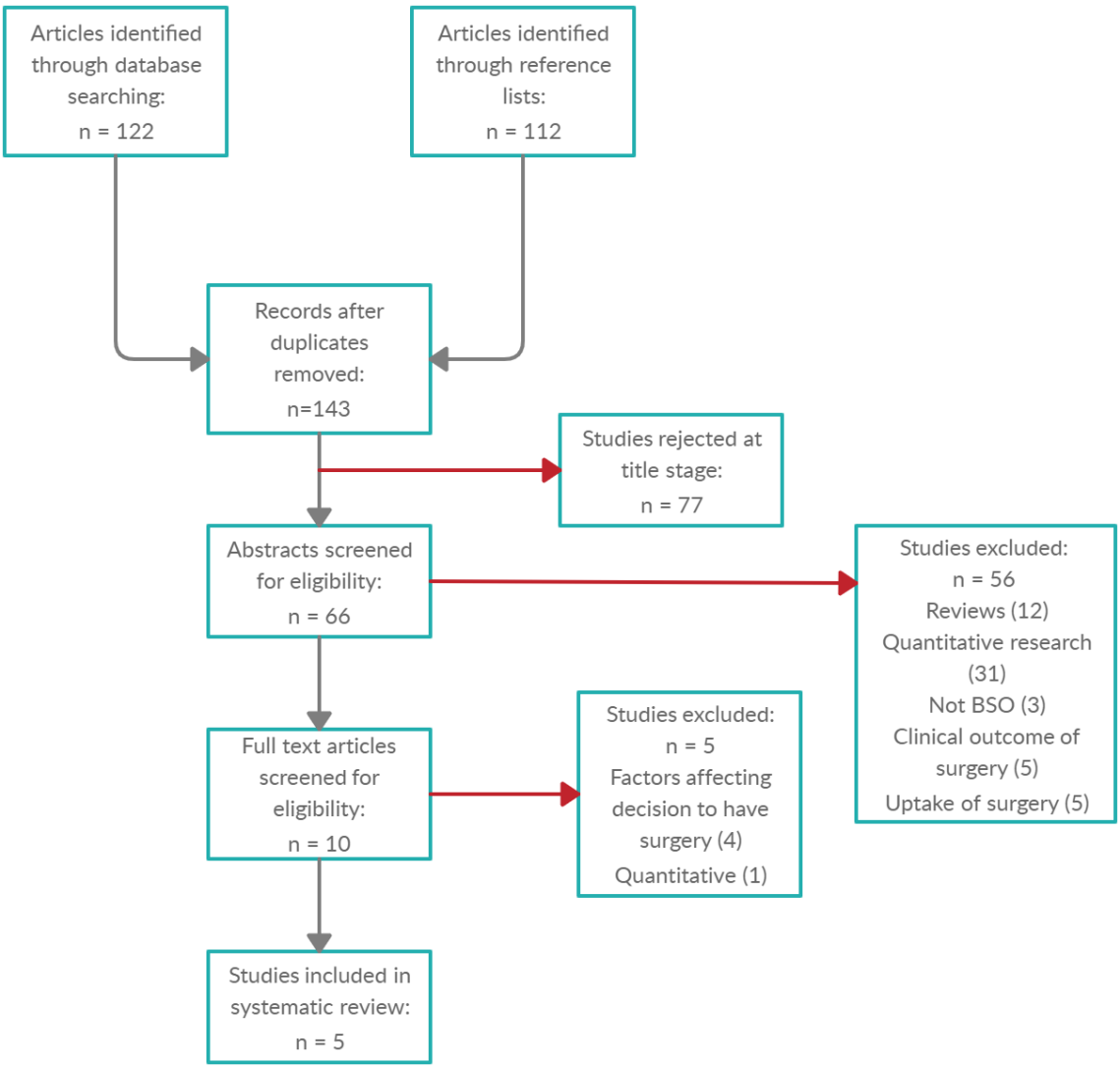

Figure 2. PRISMA flow diagram of qualitative study selection process.

Quality assessment

None of the five papers achieved full marks on the SQRQ checklist (see supplemental materials II) but no papers were ruled out based on methodological quality. The qualitative section of the MMAT was used for appraisal of the five studies (see supplemental materials III). All 5 studies were approved for analysis based on the quality assessment.

Characteristics of included studies

All five studies were retrospective interview studies conducted between 6 months and 7-years post-surgery (see Table 3 for individual study details). The five studies included data from 80 women who had had risk-reducing bilateral salpingo-oophorectomy as they were high-risk for ovarian cancer. Two studies; Hallowell and colleagues, (2000) (33) and Hallowell and colleagues, (2004) (34) use the same set of participants to explore different concepts.

Author/s	Journal	Year of publication	Country	Study design	Participants	Participant genetics (n)			Mean age (range)	Key themes
						BRCA positive	*High familial risk*[1]	*Family history of ovarian or breast cancer*		
L. A. Brotto et al. (32)	Journal of Obstetrics and Gynaecology Canada	2012	Canada	Retrospective interview	15 women had RRBSO. 11 women with BRCA mutations (group 1). 4 women had the surgery for benign gynaecological indications (group 2).	11			Group 1; 49.1 years ± 8.0 Group 2; 54.8 years ± 4.2	Preoperative knowledge of sexual side effects; preoperative drive to educate self on BSO after-effects; partner support; treatment for sexual side effects
N. Hallowell (33)	Psycho-Oncology	2000	United Kingdom	Retrospective interview	23 women who had RRBSO before age 46, were pre-menopausal prior to the operation, had two or more relatives with ovarian cancer and had no previous history of cancer.	1	21		44.4 (32-62)	Risk perceptions and cancer worry; ovarian function and then menopause; HRT; type of surgery; convalescence; risk of inheriting a genetic mutation and developing ovarian cancer
N. Hallowell et al. (34)	Genetic Testing	2004	United Kingdom	Retrospective interview	23 women who had RRBSO before age 46, were pre-menopausal prior to the operation, had two		21		Median age; 45 (32-62)	The costs of prophylactic oophorectomy; regrets: they had a few; perceived

					or more relatives with ovarian cancer and had no previous history of cancer.				benefits of prophylactic surgery
N. Hallowell et al. (35)	Familial Cancer	2012	Australia	Retrospective interview	40 women. 8 had risk-reducing mastectomy (RRM), 19 had RRBSO and 13 had both RRM and RRBSO.	25	39	43 (28-66)	Feeling different; looking different; feeling and looking different
B. Meiser et al. (36)	Psycho-Oncology	2000	Australia	Retrospective interview	14 women who had had RRBSO. 8 were known BRCA mutation carriers and 6 had unknown status. 6 women were premenopausal at the time of surgery and 4 of these were known mutation carriers.	8	14	49 (38-61)	Overall assessment of the impact of the procedure and decisional regrets; impact on levels of anxiety, impact on femininity, physical impact of surgery, sexual impact, satisfaction with support, information needs

(OC – ovarian cancer, RRBSO – risk-reducing bilateral salpingo-oophorectomy, RRM – risk-reducing mastectomy)

Table 3. Qualitative study characteristics.

[1] High familial risk of ovarian cancer – one or more first degree relative with history of breast or ovarian cancer. Individual has a 50% chance of being a carrier of a mutation.

Themes

Analysis of the studies identified five key themes. These were: (1) information needs, (2) psychological impact, (3) psychosexual impact, (4) importance of partner support and (5) impact of hormone replacement therapy (see Table 4 for details of themes identified in each study).

Study	**Theme**				
	Information needs	*Psychological impact*	*Psychosexual impact*	*Partner support*	*HRT*
Brotto et al., 2012 (32)					
Hallowell 2000 (33)					
Hallowell et al., 2004 (34)					
Hallowell et al., 2012 (35)					
Mieser et al., 2000 (36)					

Table 4. Themes identified in studies. *Green boxes show that the study provided evidence that contributed to the generation of the specific theme. Red boxes indicate that the study did not contribute to that particular theme.*

Information needs

Information about side effects of surgery

Three studies; 32, 33, 35 found that there were differing levels of knowledge about after-effects of surgery within their samples. A UK study found that 6/15 women anticipated some effect on sexual functioning but 9/15 did not (32). Women who had little knowledge of the sexual side effects reported notable distress after surgery due to after-effects. A more recent study reported a mixed response when questioned about post-surgery expectations (35). A UK study by Hallowell (33) looked specifically at the information needs of women undergoing RRBSO. Of the 23 women participating in the study, 5 were completely unaware that removal of their ovaries would result in menopause. Lack of information about menopausal symptoms led to anxiety in participants of two separate studies (33, 34). Women reported feelings of anxiety at the onset of unrecognised menopausal symptoms.

Information about HRT

Three separate studies found that women were unsatisfied with the information they received regarding hormone replacement therapy (33, 35, 36). Half of the women in the study conducted by Meiser and colleagues (36) said that they were uncertain about HRT use as they had not been provided with sufficient information to reassure them about the link between HRT and breast cancer. This is supported by the accounts of women in an Australian study who reported uncertainty around HRT use due to conflicting information from medical professionals (35). In Hallowell's study (33) of information needs 6/23 women could not remember being told about HRT and only 1 woman recalled being given a choice about which HRT she would be placed on post-surgery. Again, women in this study reported contradictory advice regarding the use of HRT, how long to take it for and the link between HRT and breast cancer.

Obtaining information

Women who had obtained information about sexual function after surgery reported that they found information through friends, the internet, support groups and books (32). Two studies (32, 33) highlighted that women experienced personal barriers to information including embarrassment and not knowing who or what to ask. Women also reported receiving inadequate information or being dismissed by their GP or gynaecologist when asking about the risks of HRT (33).

<u>Psychological impact of surgery and HRT</u>

Three studies (34, 35, 36) reported on the range of psychological effects that the surgery had on the women.

Positive impact of surgery

In all three studies the women reported feeling peace of mind and relief at the decreased cancer risk. This had a positive psychological impact on the women. In one study women also

reported positive feelings about the cessation of menstrual periods and the symptoms, such as cramps and mood swings, associated with them (35).

Negative impact of surgery

Women in one study who experienced surgical menopause said that it had a negative impact on quality of life, one women stated *'I was just frustrated, tired and upset…the fact that, God, do I have to go on like this for years? I was actually getting a bit depressed…*' (36). In another study 20/23 women reported menopausal symptoms including feeling emotional and upset (34). In a more recent Australian study, 30/32 women who had had RRBSO reported negative emotional experiences, including anxiety, mood swings and depression (35). While most women said that the positive impact of surgery outweighed the negative, there was still emotional distress post-surgery due to the onset of surgically induced menopause.

Impact of HRT

For two premenopausal women, being placed on HRT was the only way to decrease the severe emotional symptoms they had experienced after surgery (36). In one UK study, six women described positive emotional changes since taking HRT as they no longer experienced the emotional symptoms associated with their menstrual cycle (34). However, 11 women in the same study were unable to control their menopausal symptoms with HRT, which negatively impacted on their quality of life.

<u>Psychosexual impact of risk-reducing bilateral salpingo-oophorectomy</u>

All five studies reported on the changes in sexual function after surgery.

Physical impact

In Meiser and colleagues' study (36), all the women reported severe sexual dysfunction, including vaginal dryness and dyspareunia after surgery. This is supported by accounts of the women from another study who reported vaginal dryness prior to HRT (34). In a more recent study, 15/32 women commented on vaginal dryness and how painful intercourse was post-

surgery, one women quoted saying '*it is just the pain side of it, I didn't realise how dry you would be'* (35). No papers reported on the use of topical lubricants or oestrogens or the use of dilators, all tools that can be used to help with vaginal dryness and pain during intercourse (20).

Psychosexual impact

Women from all five studies reported a decrease in libido following surgery. Women on HRT reported minimal loss of libido whereas women who were unable to take HRT reported severe loss (36). In another study, women reported a lack of libido by saying *'it's complete, complete disinterest, you know complete… I don't think that they really tell you strong enough that it's a complete disinterest'* (35). Women in the same study said they had anticipated some effect on their libido but not how long it would last, many women reported being shocked by it. Four women in this study also said that the impact on their sexuality had an impact on their gender identity. One woman spoke about this in regard to losing her libido, saying '*I mean you've lost your bits and pieces but then you lose the thing that makes you feel like a woman'*. The loss of libido not only impacted on the women but also affected their relationships. Women who were more sexually active prior to surgery noted the biggest changes in the relationships due to sexual dysfunction following surgery (32). One women reported that although her husband had been informed of the potential side-effects of the surgery, he would still 'bug' her for sex and she felt as though he did not truly understand the implication of the surgery. This is supported by an account of one women whose husband thought she was sleeping with somebody else because of how little interest she had in sex post-surgery (33). At the opposite end of the spectrum, some women reported an increased in libido following surgery. Women on HRT reported that they felt liberated by the operation and no longer have to worry about unwanted pregnancies, resulting in an increased libido (34, 36).

Partner support

Two studies (32, 36) found evidence that partner support influenced the experiences of women post-surgery. In both studies, women had different experiences pre- and post-surgery.

Pre-surgery support

Pre-surgery women unanimously reported being satisfied with the support they received from their partners and said that their partners respected that it was a personal choice (32). In one study, 42% of women mentioned close female relatives who had experienced similar surgery provided them with support, offering empathy and guidance (36).

Post-surgery relationships

Many women reported problems at the onset of sexual dysfunction. This had a notable negative effect if the women were particularly sexually active with their partners prior to surgery as women who were not very sexually active prior to surgery said that their loss of libido did not impact their relationship (32). Women said that their partners expected things to go back to normal after surgery (32).

Hormone replacement therapy

All five papers had participants who were taking HRT post-surgery and were able to report on the experiences of these women.

Positive experiences

In one study (33), 6 of the 23 women reported positive side-effects of HRT. These women said they felt calmer and did not experience the mood swings that they used to associated with the menstrual cycle. In another study (36), 3/6 women were placed on HRT immediately following surgery and 2/6 women experienced such debilitating menopausal symptoms that they were prescribed HRT. These 5 women reported minimal menopausal symptoms and no decrease in libido once they began taking HRT, this was the opposite for the one women who could not take HRT as she reported severe lack of libido and depression post-surgery (36).

Negative experiences of HRT

For many women the decision-making process made them feel as if taking HRT was counterintuitive when they had just had surgery to reduce their risk of cancer (32, 33, 36). In two UK studies, 6/23 women complained of physical side effects including acne, headaches and weight gain and two women stopped taking HRT completely and three were trying to lower their dose (33, 34). Women in one study (35) said that they did not know what to expect from taking HRT as they did not know how it would work and how long they were expected to take it for.

HRT and risk

Women felt guilty and embarrassed to be on HRT as they were compromising their efforts to reduce their risk of ovarian cancer by increasing their risk of breast cancer (36). In another study women said they felt that HRT carried a cost (34). Participants from two separate studies said that they felt that there was a lack of a definitive answer from medical professionals and as a result they felt conflicted (33, 36).

Discussion

The aim of the current study was to understand the psychosexual consequences of pre-menopausal risk reducing bilateral salpingo-oophorectomy. Detailed analysis of the five qualitative papers, which focused on a range of aspects of this issue identified five themes that were pertinent to the individual experiences both before and after surgery. These themes being; (1) information needs, (2) psychological impact of surgery, (3) sexual impact of surgery, (4) partner support and (5) hormone replacement therapy use.

For pre-menopausal women, the surgery is life changing and while the majority reported an overwhelming sense of relief about their decision to take control of their cancer risk, there were still areas of unmet needs. Many women felt underprepared for the surgery and what to expect post-surgery. These unexpected changes post-surgery lead to a period of confusion

and anxiety until they were informed that they were experiencing menopausal symptoms due to the surgery. In one study, 9/15 women did not anticipate any side-effects and the 6/15 that did, obtained information from friends, family and the internet (32). This highlights an issue with the support given by medical professionals in preparation for the surgery. Women reported not feeling comfortable approaching medical professionals about sexual dysfunction post-surgery but there needs to be conscious effort pre-surgery by physicians and other health care professionals to inform women of the menopausal side-effects of the surgery in order to prepare them. It is known that women in the general population have low levels of knowledge about menopause symptoms. In one study of Pakistani women, 78.79% had little knowledge of menopausal symptoms (37). While knowledge of menopause is influenced by culture, in the Western world menopause is medicalised and many women have a poor understanding of it (38). The difference between the general population and the women who have risk-reducing surgery is that they may experience more severe menopausal symptoms due to the very sudden and severe change in oestrogen levels after surgery, in contrast to the progressive reduction seen during natural menopause (39). Women offered RRBSO should be educated pre-operatively to allow them to make informed choices about surgery and to allow them to psychologically prepare for these changes. They should also be made aware of the resources and strategies to abrogate these symptoms. The onus is on the health care professionals to ensure that the women are provided with sufficient information to make the decision whether or not to have surgery and understand the potential side-effects and treatment for these.

The positive psychological experiences reported in the qualitative studies are consistent with findings from quantitative studies. One Japanese study found significantly lower worry about the occurrence of ovarian cancer following RRBSO ($P = 0.021$) (40). A retrospective Canadian study used questionnaires to assess 96 participants' experiences following RRBSO (41). In this study there was no significant decrease in quality of life following surgery but there was a significant reduction in cancer-related psychological distress. While the surgery has positive

benefits regarding the anxiety surrounding cancer, it is not a procedure without side-effects and in some cases, the side-effects are severe enough for women to question their decision. Regrets reported in one study were mainly caused by the psychosexual sequelae following surgery (33). This is consistent with a systematic review which looked at women's regrets following risk-reducing mastectomy where factors associated with regret included psychological distress and perceived lack of information (42). This highlights the importance of informing women of the menopausal symptoms that they will experience post-surgery and the possible distress they will experience because of this.

The sexual experiences of the women were covered in multiple studies but there was no in depth understanding of the changes experienced post-surgery, either by the women or the men. One study mentioned that loss of libido made one man believe his wife had another sexual partner as she was so disinterested in sex but there was minimal exploration of the effects of loss of libido on the relationship dynamics of the couples (32). An understanding of the effects on the couple may better equip health care professionals when advising women about RRBSO. One study of 85 high-risk women who had RRBSO found that couples with higher levels of relationship satisfaction were more likely to engage in sexual relations both before and after surgery (43). High relationship satisfaction also influenced the likelihood that couples would resume having sex post-surgery despite vaginal symptoms. The importance of relationship satisfaction is something that should be stressed to both members of the couple prior to surgery. Couples with lower relationship satisfaction scores preoperatively may benefit from counselling in order to improve the relationship and possibly minimise sexual side effects experienced post-surgery. This feeds into the need for partner support both pre- and post-surgery. Women often reported feeling supported by their partner pre-surgery but when it came to having sex post-surgery, many women felt that their partners did not and could not understand why they no longer wanted to have sex. This is supported by an intervention study in which women attended a half-day educational session with take home materials (44). Following this, women experienced an increase in sexual function and self-efficacy. This again

highlights the need for better education about the sexual sequelae following surgery and the importance of women understanding how to minimise this. Educating both members of the couple on the potential side-effects and how to minimise them, where possible, may be key to ensuring that women have a positive post-surgical experience. However, engagement with male partners may be challenging.

HRT was able to alleviate some of the sexual symptoms for some women but due to the perceived increased risk of breast cancer associated with HRT use, it was not chosen by all women. Those not on HRT seemed to experience much more severe psychosexual effects. As many of the women who choose to have RRBSO are still sexually active it is important to look for other treatments that may help alleviate sexual dysfunction when HRT is not an option. Vaginal lubricants are often considered as a short-term treatment used during sexual intercourse to help with dryness and dyspareunia (20). As there are different types of lubricants; water, oil and silicone based, there are options for people with allergies and sensitivities. Topical oestrogens are also available and are an option for women who are concerned about the effects of taking systemic oestrogen replacement. While topical oestrogens only work on the vaginal effects of menopause, they have been found to work quickly and effectively. One study found that topical oestrogens were effective in reducing the rate of female sexual dysfunction (FSD) in women following RRBSO (45). There is also evidence to suggest that dilators may be effective in reliving dyspareunia through gradual stretching of the vagina (46). Dilators of different diameters can be used to gradually increase the tolerance of the vagina and decrease pain (47). However one study of gynaecological cancer survivors found that women often struggled to adhere to the regime they were given as they found it intrusive and it wasn't at the forefront of their recovery (48). Vaginal laser treatment is also an option for treating sexual dysfunction following surgery. A meta-analysis found that vaginal laser therapy was able to reduce dryness and dyspareunia due to GSM (49). Treatments like dilators and laser therapy offer options to women who do not want to take HRT and should be offered to all women following surgery. It is apparent that the sexual

dysfunction impacts the women and the couple and offering alternative solutions may help with individual quality of life and relationship satisfaction.

Limitations

The women in all studies had varying intervals between surgery and their interview and it is possible that the recollection of information is less than accurate, especially for women who have large gaps between surgery and interview or questionnaire. All of the studies conducted voluntary interviews, and therefore run the risk of sampling bias. It may be that women who responded to the invitation to interview had had polarised experiences of the procedure that they wanted to share. However, these limitations do not take away from the fact that the qualitative accounts of these women provide an insight into the surgery and recovery that cannot be gathered through quantitative research alone.

Clinical implications

Risk-reducing surgery is a life changing experience and through qualitative interviews we are able to better understand the needs of the individual's involved. Women said that they felt prepared for the physical side-effects of the surgery but the effects of menopause were unanticipated for many women. In light of this, all menopausal symptoms other should be discussed pre-operatively. Health care professionals should provide information about the real-life changes that the women will experience and the possible impacts it may have on their quality of life. Hormone replacement therapy should always be discussed with women as they often felt that they were not give sufficient information about HRT, how to use it and what it was for (36). Women should be able to make an informed decision about using HRT and if they chose not to, other options should be made available to them. It is crucial that women and their partners feel prepared for the surgery and the after-effects in order to have the most positive experience possible and the burden is on the health care professionals to provide this support.

Conclusions

Qualitative studies play an important part in forming a picture of individual experiences as they are able to address sensitive topics and quantitative studies provide numerical evidence that supports the accounts of patients. The systematic review has elucidated five factors that influence individual experiences of RRBSO and while individual experiences will vary, it has provided us with a picture of the women's needs both pre- and post-surgery. It has also identified a gap in qualitative research about the psychological impacts of the sexual dysfunction often experienced as a result of surgically induced menopause. The data obtained suggests that there is a need for better pre-surgical counselling and support post-surgery. With the advances in genetic testing, familial cancer clinics are becoming a useful support for these women and directing families to these services is beneficial. It is apparent that RRBSO has profound psychosexual effects, both positive and negative, and the studies in this paper have helped in the formation of a bigger picture which may allow us to re-evaluate the treatment of these women both pre- and post-surgery.

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Supplementary Material

Heading	Subheading		For completion by reviewer(s)
	Bibliographic details	*Circle*	Journal article Report Website Book Book chapter
	Name of reviewer		
	Eligible?	*Does the evidence fit within the scope of the review? i.e. RRBSO, outcomes, mutation carriers*	Yes No Unclear
	Typology	*Review (systematic or narrative)? Primary research? Case studies or descriptive accounts?*	
	Participants		
	Study aims	*What were the study's aims and purpose?*	
	Key findings	*What are the study's key findings?*	
	Evaluative summary	*Draw together brief comments on the study as a whole and its strengths and weaknesses. Is further work*	

		required? What are its implications for policy, practice and theory, if any?	
	Who does the study report on?	*Does the study report only on the women who had the BSO or are there other members of the family interviewed? Do the women interviewed contribute to the design/structure of the interview?*	
Ethical standards		*Was ethical committee approval obtained? Was informed consent obtained? Does the study address ethical issues adequately? Has confidentiality been maintained?*	Ethical approval: Yes No Unclear Informed consent: Yes No Unclear Confidentiality: Yes No Unclear
Context	Aims	*Are the aims and purpose of the study clearly stated?*	
	Rationale	*What is the rationale and appropriateness for this choice?*	
	Detail	*Is there sufficient detail about the setting?*	
	Timing	*Over what period did the data collection take place?*	
Sample	Inclusion criteria	*Who was included in the study?*	
	Exclusion criteria	*Who was excluded from the study?*	
	Selection	*How was the sample selected? Were there any factors that influenced how the sample was selected (e.g. access, timescale issues)?*	
	Size	*What is the size of the sample and groups comprising the study?*	
	Appropriateness	*Is the sample appropriate in terms of its ability to meet the aims of the study, the depth of data that it is enables to be collected, and its breadth?*	
Data collection	Methods	*What data collection methods were used? Was the data collection adequately described and rigorously conducted?*	

	Role of researcher	*What is the role of the researcher within the setting? Are there any potential conflicts of interest?*	
	Fieldwork	*Is the process of fieldwork adequately described?*	
	Data analysis	*How are the data analysed? How adequate is the description of the data analysis? Is adequate evidence provided to support the analysis (e.g. use of original data, iterative analysis, efforts to establish validity and reliability)? Is the study set in context in terms of findings and relevant theory?*	
	Researcher's potential bias	*Are the researcher's /researchers' own position, assumptions and possible biases outlined? Indicate how they could affect the study in terms of analysis and interpretation of the data*	
	Reflexivity	*Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?*	
	Outcomes	*Were the women satisfied/dissatisfied with their decision? What influenced their satisfaction levels?*	
	Themes	*What major/minor themes were identified? What evidence was given that supports these themes?*	
	Interventions	*What was the role of HRT in participants experience? Did it help/not help?*	

Supplemental Material I. Data extraction form.

Study reference	*Brotto et al., 2012*	*Mieser et al., 2000*	*Hallowell, 2000*	*Hallowell et al., 2012*	*Hallowell et al., 2004*
Domain 1: Research team and reflectivity					
Personal Characteristics					
1. Interviewer/facilitator Which author/s conducted the interview or focus group					
2. Credentials What were the researcher's credentials? E.g. PhD, MD					
3. Occupation What was their occupation at the time of the study?					
4. Gender Was the researcher male or female?					
5. Experience and training What experience or training did the researcher have?					
Relationship with participants					
6. Relationship established Was a relationship established prior to study commencement?					
7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research					
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic					
Domain 2: study design					
Theoretical framework					
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis					
Participant selection					

10. How were participants selected e.g. purposive, convenience, consecutive, snowball					
11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email					
12. Sample size How many participants were in the study?					
13. Non-participation How many people refused to participate or dropped out? Reasons?					
Setting					
14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace					
15. Presence of non-participants Was anyone else present besides the participants and researchers?					
16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date					
Data collection					
17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?					
18. Repeat interviews Were repeat interviews carried out? If yes, how many?					
19. Audio/visual recording Did the research use audio or visual recording to collect the data?					
20. Field notes Were field notes made during and/or after the interview or focus group?					
21. Duration What was the duration of the interviews or focus group?					
22. Data saturation Was data saturation discussed?					
23. Transcripts returned Were transcripts returned to participants for comment and/or correction?					
Domain 3: analysis and findings					
Data analysis					
24. Number of data coders How many data coders coded the data?					
25. Description of the coding tree					

Did authors provide a description of the coding tree?					
26. Derivation of themes Were themes identified in advance or derived from the data?					
27. Software What software, if applicable, was used to manage the data?		Kwalitan	Atlas-ti	NVIVO8	Atlas-ti
28. Participant checking Did participants provide feedback on the findings?					
Reporting					
29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number					
30. Data and findings consistent Was there consistency between the data presented and the findings?					
31. Clarity of major themes Were major themes clearly presented in the findings?					
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?					

Supplemental Material II. SRQR analysis for methodological quality. Green boxes highlight where criteria reported. Red boxes highlight where criteria were not met.

	Brotto et al., 2012	**Hallowell 2000**	**Hallowell et al., 2004**	**Hallowell et al., 2012**	**Meiser et al., 2000**
Methodological criteria					
Screening questions					
S1. Are there clear research questions?	+	+	+	+	+
S2. Do the collected data allow to address the research questions?	+	+	+	+	+
Qualitative research					
1. Is the qualitative approach appropriate to answer the research question?	+	+	+	+	+
2. Are the qualitative data collection methods adequate to address the research question?	+	+	+	+	+
3. Are the findings adequately derived from the data?	+	+	+	+	+
4. Is the interpretation of results sufficiently substantiated by data?	+	+	+	+	+

5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	+	+	+	+	+

Supplemental Materials III. Mixed Methods Appraisal Tool Checklist for qualitative research.