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for *Familial Cancer*

Looking different, feeling different: Women's reactions to risk-reducing breast and ovarian surgery

Nina Hallowell¹, Brandi Baylock^{2,3}, Louise Heiniger^{2,3}, Phyllis N Butow^{2,3}, Deepa Patel^{2,3}, Bettina Meiser⁴
kConFab Psychosocial Group on behalf of the kConFab Investigators, Melanie A Price^{2,3}

1. Institute of Health and Society, Newcastle University, UK
2. Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), The University of Sydney, NSW, Australia
3. School of Psychology, The University of Sydney, NSW, Australia
4. Prince of Wales Clinical School, University of New South Wales, Kensington, NSW, Australia

Address for Correspondence

Nina Hallowell, Institute of Health & Society, Baddiley-Clark Building, Richardson Road, Newcastle Upon Tyne,
NE2 4AX UK

Email: Nina.Hallowell@ncl.ac.uk

Phone:

Fax:

Looking different, feeling different: high risk women's reactions to risk-reducing breast and ovarian surgery**Abstract**

Objectives Most studies of quality of life following risk-reducing bilateral salpingo-oophorectomy (RRSO) and mastectomy (RRM) for inherited breast and ovarian cancer susceptibility were conducted before counseling protocols were established and included women at varying times since surgery. This study aimed to overcome these deficiencies and to provide current data on outcomes for this growing group of women.

Methods Semi-structured interviews were used to explore the experiences of an Australian cohort of 40 high-risk women three years after they underwent RRM and/or RRSO. Data were analyzed using the method of constant comparison.

Results Nineteen women underwent RRSO, 8 RRM and 13 both procedures. Two themes – *looking different* and *feeling different* - captured the psychosocial impact of surgery upon interviewees. All were relieved at having the risk of cancer substantially reduced that had previously been embodied in their breasts and ovaries; however, reducing risk by removing these body parts is not without costs. Interviewees reported experiencing a range of negative emotions and a range of unexpected bodily sensations following surgery and reflected upon both positive and negative changes in their appearance. Women said they had been unprepared for the lack of sensation in reconstructed breasts and/or the severity of menopausal symptoms, which often had a negative impact upon sexuality.

Conclusions Although women who undergo RR surgery are informed about its sequelae, however, few are entirely prepared for the reality of undergoing this procedure. We recommend that women who undergo these procedures should be provided with psychosocial support before **and** after RR surgery.

Key words: *BRCA1* and *BRCA2*, breast and ovarian cancer, risk-reducing surgery, qualitative, sexuality and body image.

Introduction

In about 20-30% of families the occurrence of breast and ovarian cancer in multiple family members is due to a germline mutation in the *BRCA1* or *BRCA2* gene. Between 30-50% of breast cancers that have an inherited susceptibility are caused by mutations in the *BRCA1* or *BRCA2* genes, while as many as 13% of invasive epithelial ovarian cancers have a mutation in *BRCA1* or *BRCA2* independent of family history [1].

Although *BRCA1* and *BRCA2* mutation carriers' cancer risks are increased [2, 3], evidence suggests that these risks can be managed effectively [4-7]. While ovarian screening in high-risk groups is not effective, breast cancer screening is indicated and there is evidence of increased sensitivity of magnetic resonance imaging (MRI) for detecting malignancies in younger *BRCA* carriers [8, 9], compared to mammography. Risk-reducing mastectomy (RRM) and/or oophorectomy (RRSO) results in a significant decrease in mortality in high-risk women [6, 7, 10, 11]. Domcheck et al [11] found that RRSO was associated with lower all-cause mortality, as well as lower breast cancer-specific and ovarian cancer-specific mortality. Recent data suggest that a combination of RRM and RRSO at 40 years is the most effective way to improve survival in *BRCA* mutation carriers, and that performing RRM any earlier has little impact upon survival rates [13]. Risk-reducing medication with selective estrogen receptor modulators (e.g. tamoxifen) is also an effective way of reducing breast cancer risk [14].

A number of studies that have investigated the psychosocial sequelae of RR surgery suggest these procedures are associated with a decrease in cancer anxiety [15-17]. However, while many women who have RRM plus breast reconstruction are pleased with the appearance of their new breasts [18-20], some experience ongoing complications following reconstructive surgery [21, 22]; are unhappy with the cosmetic result, particularly the lack of sensation in their breasts [22-24]; and report a negative impact upon sexual functioning [15, 22, 25, 26]. Similar findings have been reported in studies of RRSO, which indicate that some symptoms of surgically induced menopause, primarily hot flushes and loss of libido, are experienced negatively by women who undergo RRSO [27]. Bonadies, Moyer, & Matloff [28] suggest that there are gaps in the information that is provided by healthcare professionals before surgery. This study found that 60% (3/5) of the most common symptoms experienced by women post-surgery were not discussed beforehand [28].

There are a number of problems with psychosocial research in this area. First, almost all studies have collected data using forced choice questions [14, 29, 30], which means that findings are more likely to reflect researchers', rather than patients', views and perceptions. Second, the time since surgery in some studies was very

variable, indeed, in some cases [21, 31] data was collected many years after surgery, raising the possibility of recall bias. Finally, many studies were undertaken before protocols for counseling women about RR surgery were established; indeed, in some of the earlier research many women had not received genetic counseling or much information prior to surgery [26, 30]. These observations suggest there is a need for up to date research that seeks to understand the meaning of these surgical procedures within the wider context of women's lives and determines whether their information needs are now being met.

Methods

Recruitment

Participants were recruited from the Kathleen Cuninghame Foundation Consortium for Research into Familial Breast Cancer (kConFab) Psychosocial study, an 11-year prospective study of over 2,600 women, with no personal history of cancer (except non-melanoma skin cancer or cervical intraepithelial neoplasia CIN I-III), but with a strong family history of breast and/or ovarian cancer or a documented *BRCA1* or *BRCA2* mutation [32]. kConFab (www.kconfab.org) is a genetic, epidemiological, medical and clinical data resource of individuals at increased familial risk of breast cancer across Australia and New Zealand. Eligibility criteria for entry into kConFab have been previously published [32]. At the time of enrolment to kConFab, blood is drawn for potential mutation analysis, and an epidemiology and family history questionnaire is completed. Two sub-studies, the Clinical Follow-up Study and the Psychosocial Study, are conducted in parallel, collecting clinical follow-up and psychosocial data at three-yearly intervals, using self-report questionnaires and a semi-structured interview [33].

The research reported below was undertaken as part of a larger study investigating psychosocial predictors of uptake, and long-term outcomes, of risk-reducing surgery within the kConFab Psychosocial Study cohort. To be eligible for the current study, women had no personal history of cancer (exceptions noted above) at the time of cohort enrolment, and subsequently undergone an RRM or RRSO. Eligible women were invited to participate in a telephone interview three years after their risk-reducing surgery.

Data Collection and Analysis

This study was approved by the University of Sydney Human Research Ethics Committee and institutional ethics committees at each kConFab recruitment site. Semi-structured interviews were conducted from September 2006 to January 2009. Open-ended questions focused upon: surgical decision-making, information needs, perceived costs

and benefits of surgery, risk perception, pre-surgery expectations and knowledge, experiences of surgery and convalescence, menopause and HRT use, and overall satisfaction with the surgical decision. Interviews were audio-recorded and verbatim transcriptions obtained.

To determine the meaning of RR surgery in women's lives, a thematic qualitative analysis was undertaken. A subset of transcripts were read by NH, DC, LH and BB and a list of broad categories referring to women's experiences of RR surgery was generated. The transcripts were (re)read in the light of this initial categorization and a coding scheme developed using the method of constant comparison [33]. This scheme was used to code the remaining transcripts (BB and LH) and was revised as the analysis progressed. Finally, the emergent codes were collapsed into higher order themes. A subset of transcripts was independently recoded to determine inter-coder concordance. Data was managed using NVIVO8 (Qualitative Solutions & Research Pty Ltd, 2008).

Results

The participants

Table 1 here

Table 1 shows the sociodemographic and medical characteristics of the sample. Forty women who had undergone RRSO or RRM between April 2003 and January 2006 (hereafter primary RR surgery) were recruited approximately three years later. Eight women had RRM only, 19 RRSO only, and 13 had undergone both procedures (two had both types of surgery at the same time and four underwent the second operation within the three year period). The mean age at primary surgery was 43 (range 28-66) years. The mean time since primary RR surgery was 37 (range 34-40) months. Twenty-five women (63%) carried a *BRCA1* or *BRCA2* mutation. Thirty-nine (98%) women had one or more (range 0-4) first-degree relatives, and 36 (90%) had one or more (range 0-3) second-degree relatives, with breast and/or ovarian cancer.

Nineteen (90%) of the 21 women who had RRM underwent breast reconstruction (15 implants, 4 transverse rectus abdominus myocutaneous (TRAM) flap procedure). Of the 32 women who had RRSO, 21 (66%) also had a total hysterectomy (not necessarily at the same time). Only six of the 32 (19%) women who had undergone RRSO, were post-menopausal prior to surgery (mean age 55 (range 48-61) years). Eighteen of the 32 (56%) women used hormone replacement therapy (HRT) post-oophorectomy, and 14 (44%) were still taking HRT at the time of interview.

The interview data

When describing RR surgery women focused upon the way it made them feel and how it affected their appearance, thus the data generated two main themes – *feeling different* and *looking different*. Some differences were discerned regarding the impact of breast versus ovarian surgery and these are highlighted in the analysis. Women who had breast surgery only are indicated by the prefix ‘B’, those who had ovarian surgery only ‘O’ and those who had both types of surgery ‘BO’. Menopausal status prior to RRSO is indicated for those who underwent RRSO (premenopausal (‘premen’)).

Feeling different

Nearly all interviewees reported being less worried about developing cancer following RR surgery; many used tried and trusted metaphors to portray the emotional impact of surgery, describing it as providing “peace of mind” (BO1, premen) and the reduction of risk as similar to the eradication of “a black cloud” or “the sword of Damocles that hovers overhead” (B4).

While the removal of risky breast/ovarian tissue, and with it the fear about developing cancer, was seen as taking positive action, for some women RR surgery generated unforeseen negative emotions. A few described “grieving” (O16, premen) for their ovaries (lost fertility) and breasts (“the sadness of not being able to breastfeed” - B3). Others experienced negative emotions because they failed to anticipate what losing their breasts or ovaries would feel like. In sum, women experienced a range of negative emotions post-surgery including feeling: “grumpy”, “angry”, “blue”, “depressed”, “miserable”, “emotional”, “aggressive”, “anxious”, “agitated”, “a bit snaky”, “emotional”, “on a downer”, “on an emotional rollercoaster” and “irritable”.

Many women who had RRSO attributed some of these emotional changes to the menopause, whereas participants who underwent RRM saw their negative emotions as a caused by the loss of their breasts.

B2: I’m not sure what it was but I was extremely emotional. It didn’t last that long but yeah, it was terrible. I remember just going to bed and wanting to be up at the dinner table but I had tea and I just had to go and lie down and I just cried because I thought I can’t involve myself in anything.

Feeling different – risk-reducing mastectomy

Unanticipated bodily sensations following RRM were common. Many who had reconstruction reported that their breasts felt different - hard and unyielding - and no longer moved in a naturalistic way. Some experienced uncomfortable sensations and had to adopt different sleeping positions, while others described their breasts as numb or lacking in sensation and their breast implants as feeling alien.

B6: They're just there. I feel like I've got a tight bandage wrapped around me all the time. They're not comfortable....they're just there and you sort of feel all the scar tissue inside There is no sensation and you feel like you are cold in the chest all the time because they don't warm up like your normal body does.'

A few women said they experienced abdominal numbness or pain after having abdominal tissue removed for TRAM flap reconstruction. They described having to be careful of the types of activities they undertook or when buying clothes because exercise could pull or clothing could rub against abdominal scars.

B4: ...that section of muscle area across the abdomen and that scar line that's sort of along the bikini line that troubles me at times if I have been lifting a lot of heavy groceries or doing anything particularly sort of physical.

Although most women who had undergone RRM and reconstruction had expected to feel pain after these procedures, in some cases the severity and duration of pain was greater than anticipated.

B3: I knew I'd be in a bit of pain after surgery but I didn't really realize, I'd never been through that kind of pain before so you can't really prepare for that.

While post-surgical pain was transient, other changing bodily sensations were long-lasting with negative psychosocial repercussions. A small group talked about how the (lack of) sensation in their reconstructed breasts had negatively affected their sexuality, while others said that until they had adapted to their new breasts, having sexual relations had been painful.

B1: I don't like my husband touching them (breasts) that much... they don't feel uncomfortable but it feels like you're touching a rock on you kind of thing and I can't feel it.

B4: it was actually very sore, that sort of chest to chest contact, during sex - just my breasts couldn't take a lot of weight on them But you just get into different positions.

Feeling different – risk-reducing salpingo-oophorectomy

Those who underwent RRSO described the emotional and sensational impact of menopause upon their lives.

BO4 (premen): I thought I was going to drop dead at one point...I started getting these real severe sweats and hot flushes and the insomnia set in and it was like somebody had thrown a brick at me. You know one day I'm fine and then the next day it's a totally different story.

While a couple of women were positive about cessation of menstruation and menstrual symptoms, most reported multiple negative symptoms including: hot flushes, incontinence, excess hair, night sweats, weight gain, lack of libido, vaginal dryness/pain during intercourse, anxiety/panic, forgetfulness, heart palpitations, shakiness, "creepy crawly skin", mood swings, depression, dry skin, insomnia, and headaches.

Some women who were pre-menopausal prior to RRSO had few expectations about the actual symptoms of menopause; others reported being very well-informed, but nearly all had expected some mood swings and hot flushes and some impact on their sexuality. However, few women who were pre-menopausal before RRSO reported

being prepared for either the severity of menopausal symptoms (particularly, hot flashes) or their speed of onset. As O10 (premen) commented, “I was aware of what to expect ...but the severity of it I did not understand.” Indeed, the consensus regarding surgical menopause was despite being aware of what could happen “...you really don’t know until you’re going through it” (O9, premen).

Participants expressed uncertainty about the use of HRT. Unanticipated issues included: the difficulties balancing hormone levels, experiencing side-effects, HRT that did not work and confusion before and after surgery about whether to use HRT. Few knew what to expect from HRT, how long it would take to work or how long to use it.

BO5 (premen): Well I would have liked to have known what HRT was...all the different types of HRT, the fact that one doesn’t suit everybody, different dosages, different brands even affect different people differently. Um I guess I still have even unanswered questions like I’m in my 40s now, do I need to take this forever or what.

These uncertainties led to some participants not using HRT or other alternatives.

O8 (premen): ...I would have liked to have known more about the alternatives (to HRT) for high-risk women...five years down the track I really don’t know how...I really don’t know but I just don’t take it because that’s what I believe.

Women who had RRSO commented upon the negative effect on their sexuality. Some talked about vaginal dryness and how painful intercourse had become since surgery. As O9 (premen) said, “It is just the pain side of it, I didn’t realize how dry you would be and I just felt like that, my husband’s changed towards it as well”. Others talked about their lack of libido post-oophorectomy.

O8 (premen):...more than just a lack of libido, it’s complete, complete disinterest, you know complete – I don’t know how to put it,I don’t think that they really tell you strongly enough that it’s a complete disinterest.

Although many had anticipated that RRSO would impact on their libido, they had not expected these symptoms to be so profound or long-lasting. For some their lack of sexual desire was experienced as having profoundly negative implications for their identity.

O19 (premen):...it’s a shame that they can (remove your ovaries) and they can’t replace the estrogen or whatever that gives you that sexual drive... I mean you’ve lost your bits and pieces but then you lose that thing that makes you feel like a woman.

Thus, in contrast to women who had undergone RRM, who reported feeling more feminine following surgery, some RRSO participants experienced RR surgery and the accompanying impact on their sexuality as having a negative impact on gender identity.

BO4 (premen): with the mastectomy I didn’t feel as feminine as I didn’t have my breasts, but with the hysterectomy and the ovaries - that really affected me. I’ve got to admit that truly affected me. I just thought that was the only woman bit I had left.

In summary, the data suggest that many women feel differently about their bodies following RR surgery. Most felt less anxious about the risk of cancer in their breasts and ovaries; however reducing risk by removing breasts and ovaries was acknowledged as carrying a number of costs. Women reported experiencing a range of negative emotions and a series of new, and mainly negative, bodily sensations following surgery. While many of these changes had been anticipated, it was clear that their intensity and duration had surprised many interviewees.

Looking different – risk-reducing mastectomy

While surgery generated some unexpected feelings, it also impacted on the way one looked. Women who had RRM plus reconstruction often described visible improvements. The opportunity to change breast shape and size with reconstruction following RRM was described as a bonus. “I ended up with a better bust than I had before so I was happy” (B5). All those who had RRM had ended up with firmer breasts and many talked about how they could wear more skimpy, or sexy, clothing.

B7: I love it now because I mean it’s just sort of, I could go without a bra if I wanted to because I don’t... like I’ve never not been able to wear a bra, I was a double D cup, so I went to a C cup and I can go in a singlet without having to wear a bra because they’re not sort of... they’re like when I was 20 again.

For a small group, TRAM flap reconstruction also involved an incidental bonus. As BO14 (menopausal), said: “I had a very big bust and so I got it reduced. Plus I got a tummy tuck into the bargain”. However, some were distressed by the cosmetic results, like BO1: “I’ve got this train track that goes right across my breast”, or the different shape of their breasts. Finding clothing to cover the scars was difficult for some, while others said their breasts sat differently, constraining their wardrobe choices.

Many women were conscious of both breast and abdominal scarring following TRAM flap breast reconstruction, and a couple said that they no longer liked their reflection in the mirror. In general, abdominal scarring was not regarded as so much of a problem as breast scarring. It took time for many women to get used to the look of their new body. Those who had breast implants felt self-conscious at first and commented that their breasts did not sit properly on their chest. Others just did not like the look of their implants, including the way they moved; as B6 said “they’re not attractive, they are ugly.”

Some RRM women regretted not having nipple reconstruction. As B4 said “like standing naked in front of the mirror it’s sort of okay, well they’re a nice shape but it would be really nice if I still had nipples”. B3 reported that not having nipples had affected her sexuality as she did not like her partner seeing her naked anymore. Finally,

one woman who had not had reconstructive surgery still found it difficult to accept the look of her mastectomized body.

BO2 (premen): ... my kids say they don't know whether I'm wearing it [prosthesis] or not I still have those things where they assure me that everything is perfectly okay and my husband still adores me and everything and that's wonderful, but it's in my head still, that hang on I made this decision and I really, I think I look really different.

Finally, there was evidence that while most women were prepared for changes in their appearance post-surgery, their expectations were not always met. While some were pleasantly surprised, like BO5 (premen), "I had not expected the reconstruction to turn out as good as it had. I'm really pleased with it," many were still distressed about scarring, and the actual changes were of a greater magnitude, or more long-lasting, than expected. BO1 (premen): "I hadn't expected them [breasts] to sort of look like you know, as I said I didn't expect the scarring to still be there."

Looking different – risk-reducing salpino-oophorectomy

While gross differences in the visibility of RRM and RRSO were recognized in these accounts "with the ovaries there was the keyhole surgery, you're in and out really quickly and you don't look any different when you walked out of the hospital... whereas obviously the mastectomy was a much bigger operation... like everybody can see" (BO1, premen). There was an acknowledgement that RRSO still wrought subtle changes upon the body, while scarring was less of an issue for this group, many reflected upon post-surgical weight gain and how their body shape, especially fat distribution, had changed. As O3 said about her weight gain: "I'm getting a little bit – a tiny little bit of a tummy, like I said I've always been very athletic and very slim." Other women were very negative about this effect of surgery describing post-surgical weight gain as making them feel less attractive. O16: "...putting on the weight...different shape.... I don't know if it affects my life, it just makes me feel less attractive..." However, in the main these bodily changes were anticipated and regarded as physical transformations that would have occurred naturally with time.

Feeling and looking different

As O16's comments (above) suggest, this analysis draws a somewhat artificial distinction between how women feel following RR surgery and how they look, for it is apparent that in many cases how these women felt about themselves was clearly related to how they looked. Many talked about how surgery had affected their identity. B2, for example, had feared her gender identity would be compromised by RRM, but found the opposite occurred:

B2: You probably expect part of your womanhood as such being taken away, but I actually feel so much more a woman now...while my breasts aren't perfect I'm very happy with what I've got...and I just feel a lot more confident in myself.

In contrast, BO11 described still trying to come to terms with surgery and actively having to try to incorporate the look of her new body into her identity.

BO11 (premen): I call them brumps, they're not really breasts and not really lumps so ...Whatever they are...I went back last year and had some nipples [constructed] ...I'll probably have the tattoos done...it is ongoing but I am going to persevere with it and try and make myself feel like they're a part of me.

Indeed, for most interviewees, the impact of surgery on their emotional life and appearance were intimately related for better or worse.

Discussion

This study found that women who undergo risk-reducing breast and/or ovarian surgery to reduce their risk of cancer, experience a range of positive and negative psychosocial consequences. Like previous research, this study suggests that women who undergo RR surgery have a positive emotional response to the reduction in their breast and/or ovarian cancer risk [25, 35] and often like the look of their reconstructed breasts [18-20]. However, they also described a range of negative psychosocial sequelae associated with these surgical procedures. Although the majority underwent these procedures with a number of expectations about how the surgery might affect them, the findings reveal that the impact of surgery had surpassed their expectations in many ways.

Many of the women who underwent RRM plus reconstruction commented on the numbness, pain and discomfort they experienced as a result of surgery, and described how these sensations negatively affected their everyday activities (sleeping, moving around, sport) as well as their sexuality [36] and body image. While earlier studies suggest that sexual functioning is not compromised by RRM, there is evidence that about half of the women who undergo this procedure report some issues with body image and sexuality [15, 19, 21], like the women in this study. Our study suggests that while many of our interviewees had some expectations of how their breasts might look post-surgery, few had any realistic expectations about the changes in sensation in their breasts, changes which were uniformly experienced as disturbing.

There was evidence that the premenopausal women who underwent RRSO were relatively well-informed about some of the menopausal symptoms they might experience post-surgery (e.g. hot flushes and loss of libido);

however, their intensity and speed of onset was not anticipated. Indeed, many women were shocked at their lack of libido following RRSO. These observations support the findings of a recent study, which found that nearly 60% of BRCA carriers who had undergone RRSO would have liked more information about the impact on their sex lives and to be given the option of sex counseling [28]. While many of our interviewees reported that they had expected to look different after ovarian surgery - they had expected scarring (particularly following TAH) and anticipated that they might gain weight following RRSO - few accurately predicted the magnitude of these changes or the impact on body image. This was particularly true for those women who had been pre-menopausal before surgery.

Strengths and Limitations

The strength of the current study is that all participants were interviewed at the same time point - three years after surgery. As a result, while the data may be tainted by hindsight, the impact of time on recall is constant and any inconsistencies in the reporting of experiences that arise due to variations in the women's location on the recovery trajectory are minimized. Moreover, as all had undergone surgery during the same time period, any guidelines on how to provide information or support, e.g. [37] were consistent across our sample. These strengths address a limitation of earlier studies in this area that have investigated the consequences of RR surgery at varying time points after surgery [21, 31].

However, as with all research of this type there is a potential that this study includes a biased sample; that only those who had polarized issues around surgery may have consented to be interviewed. It is also possible that there is something significant about the three-year post-surgery time point at which these women were interviewed. Bearing this in mind we suggest that future research should adopt a longitudinal design, in which women are interviewed at different time points to determine changes in their experiences and attitudes.

Clinical implications

This study suggests that while many women correctly anticipate many of the visible sequelae of risk-reducing surgery, it is also apparent that many remain unprepared for the changes in the way their bodies feel [21, 24, 26, 36] and the ways they may feel about themselves [15, 21, 25, 27, 38] following surgery. While health care professionals may do their best to prepare women for physical changes, pain, scarring and reduced libido, there is evidence that the impact upon sexuality, body image and gender identity are not routinely discussed by surgeons and, in line with

recommendations made in recent papers [28], we argue that these issues are important topics for discussion in pre-operative consultations.

Before proposing recommendations for clinical practice, we want to draw attention to the fact that all health professionals involved in the care of high-risk women, including those working in familial cancer clinics, breast surgeons and/or gynecologists, need to be forthcoming in explaining RR surgery and its psychosocial after-effects. It cannot be assumed that health professionals who have had previous contact with a woman have adequately addressed this area.

First, women need to know that reconstructed breasts may look better, but alternatively could look worse than their original breasts, and may, in either case, feel very different, particularly if implants are used. The South Australia Familial Cancer Clinic has developed an information leaflet about this which graphically describes the shape, sensation of reconstructed breasts and how this may impact on one's life and sexuality [39]. Similar information should be given to all those who undergo this procedure.

Second, women need to be encouraged to consider the impact that both types of RR surgery may have on their sexuality and/or gender identity, as these impacts, in particular, may have ongoing and negative implications for their relationships. They need to be proactively provided with strategies to facilitate sexual adjustment should difficulties ensue.

Third, women need more information about surgical menopause, what it may feel like and how fast the symptoms present following RRSO. Notably, young women in their thirties and early forties are unlikely to have discussed menopause with their peers, and in many of these families women in older generations have not survived long enough to go through a natural menopause; therefore the information about symptoms, what they feel like or their impact, may not be passed down from mother to daughter. The risk of other adverse effects, such as cognitive impairment in women undergoing RRSO prior to menopause, should also be discussed [40]. Women also need information about the costs and benefits of HRT. Indeed, recent research suggests HRT may be beneficial not only for alleviating menopausal symptoms, but also in preventing bone loss, and promoting cardiovascular health in women who have undergone RRSO under 50 years of age [41].

Finally, women should be warned that RRSO may have as much, if not more, of an impact than RRM. While ovarian surgery may result in less obvious and immediate outward changes to women's bodies, its ongoing detrimental effect on women's lives can be equally, if not more, profound. We suggest that younger premenopausal

women who are considering RRSO should be offered a clinical psychological consultation as is current practice for women who are contemplating RRM.

But not only is improved pre-surgical counseling indicated, our data suggest that up to three years after surgery women may still be adjusting to these procedures and therefore, may also benefit from long-term psychosexual follow-up. Familial cancer clinics, which provide long-term follow up for these high risk families, may be best-placed to provide such a service.

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The kConFab Psychosocial Group includes the following in addition to the authors listed in the author group: B Bennett & K Tucker, Department of Medical Oncology, Prince of Wales Hospital, Randwick, Australia. S-A McLachlan Department of Oncology and Department of Medicine, St Vincent's Hospital, Melbourne, Australia; K-A Phillips, Department of Medicine, St Vincent's Hospital, University of Melbourne, Melbourne, Australia; Division of Cancer Medicine, Peter MacCallum Cancer Centre, Victoria, Australia; School of Population Health, University of Melbourne; CC Tennant, Sydney Medical School (Northern), The University of Sydney, Sydney, Australia.

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Table 1: Participant characteristics (N=40)

	RRM N=8 (20%)	RRSO N=19 (48%)	RRM+RRSO = 13 (33%)	Total = 40 (100%)
AGE AT PRIMARY RR SURGERY years mean (range)	34 (28-41)	44 (33-61)	46 (32-66)	43 (28-66)
MARITAL STATUS				
Married / de facto	6 (75)	19 (100)	10 (77)	35 (88)
No current partner	2 (25)	0 (0)	3 (23)	5 (13)
CHILDREN (yes)	6 (75)	18 (95)	11 (85)	35 (88)
Boys only	3 (38)	1 (5)	3 (23)	7 (18)
Girls only	0 (0)	7 (37)	2 (15)	9 (23)
Both	3 (38)	10 (53)	6 (46)	19 (48)
EMPLOYMENT				
Employed	4 (50)	17 (90)	6 (47)	27 (68)
Domestic duties	2 (25)	1 (5)	3 (23)	6 (15)
Retired / Invalid	0 (0)	1 (5)	3 (23)	4 (10)
Student	2 (25)	0 (0)	1 (8)	3 (8)
HIGHEST EDUCATION ACHIEVED				
Secondary Education	2 (25)	10 (53)	7 (54)	19 (48)
Vocational training	3 (38)	9 (47)	1 (8)	13 (33)
University graduate	3 (38)	0 (0)	5 (38)	8 (20)
FAMILY HISTORY				
FDR/SDR breast cancer	8 (100)	19 (100)	13 (100)	40 (100)
FDR/SDR ovarian cancer	2 (25)	7 (37)	8 (62)	17 (89)
HRT use				
Never	8 (100)	9 (47)	2 (15)	19 (48)
Before surgery	0 (0)	1 (5)	2 (15)	19 (48)
After surgery	0 (0)	9 (47)	9 (69)	13 (33)
At time of interview	0 (0)	6 (32)	8 (62)	8 (20)