Sexual Function and the Information Needs of Women after Risk-Reducing Salpingo-Oophorectomy

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Abstract

Objectives: To investigate the recall of pre-operative discussions about sexuality and to test for association with current sexual function for women who have undergone risk-reducing salpingo-oophorectomy (RRSO). To identify the information needs of women undergoing this procedure.

Method: Cross-sectional, questionnaire study of women who have undergone RRSO. The recollections of pre-operative discussion of specific topics were assessed, as was the preferred amount of information. The questionnaire included open-ended questions requesting recommendations for improvement. Previously collected data of sexual function for this study cohort was available.

Results: Sixty-one out of 102 eligible participants (60%) responded. Discussion of at least one topic of sexuality was recalled by 72% (n=44). No association was observed between current sexual function and pre-operative discussion of sexuality (p=0.548). Older and post-menopausal women recalled less pre-operative discussion of sexuality (p=0.005 and 0.023 respectively). Areas highlighted by participants for improvement were: access to additional sources of information, timing of information given, psychological impact, surgical information, menopause management, and greater detail in general.

Conclusion: In this study there was no association between recollection of pre-operative discussions about sexuality and current sexual function. Healthcare professionals counseling women prior to RRSO should consider recommending additional sources of information regarding the potential impact of surgery on sexuality, such as written material and referral to a menopause clinic. It is important for healthcare professionals to acknowledge the psychological significance of RRSO and to allow women sufficient time to process information before surgery.

INTRODUCTION

Despite research efforts in recent years focused on improved detection and treatment, ovarian cancer remains a highly lethal malignancy with the majority of women being diagnosed at an advanced stage [1]. The risk of developing ovarian cancer is significantly increased in women with specific familial cancer syndromes or a family history of ovarian cancer [2,3]. In particular, women with the hereditary breast ovarian cancer syndrome caused by germ line mutations in the BRCA 1 and 2 genes have a 59% and 16.5% lifetime risk of ovarian cancer respectively [2], while those with Lynch Syndrome caused by mutations in DNA mismatch repair genes, have a lifetime risk of 8% [4].

Current guidelines recommend women at increased risk of ovarian cancer undergo the prophylactic removal of their ovaries and fallopian tubes at age 35-40, once child bearing is complete [5]. This procedure, termed risk-reducing salpingo-oophorectomy (RRSO), often renders these women prematurely menopausal and may have adverse effects on sexual function with high rates of low libido, vaginal dryness, dyspareunia, and orgasm difficulty being reported [6-9]. These sexual difficulties have been linked to patient regret following surgery [8], however, one study found that those who sought information regarding the potential sexual sequelae prior to surgery, felt better prepared for the operation and subsequently did not experience sexual symptoms [10]. The aim of the current study was to investigate the recollections of women who had undergone RRSO, regarding pre-operative discussions about sexuality and to test for association with current sexual function. Secondary aims were to determine factors which may influence rates of pre-operative sexuality discussions, and to identify the information needs of women undergoing RRSO.

MATERIALS AND METHODS

Study design

A cross-sectional study of women who had undergone RRSO was conducted with participants completing a questionnaire regarding their recollections of pre-operative sexuality discussions and recommendations for improvement.

Setting

The study was undertaken at the Department of Gynaecologic Oncology, St John of God Subiaco Hospital (SJOG), and a tertiary private hospital in Perth, Western Australia. This study was reviewed and granted ethics approval by the St John of God Healthcare Human Research Ethics Committee (HREC) and the University Notre Dame Fremantle HREC. Participants were recruited between August and November 2015. In total 102 women were eligible and were invited to participate.

Participants

Participants were identified from the records of three consultant gynaecologic oncologists at SJOG. Women were eligible to participate if they had undergone RRSO between January 1st 2009 and December 31st 2014. Exclusion criteria were: a suspected gynaecologic malignancy, major psychiatric illness, intellectual impairment, and limited English language skills.

Data sources

Data was collected via questionnaire which included questions regarding: the timing of discussions of 9 specific sexual issues (vaginal dryness, reduced libido, dyspareunia, orgasm difficulty, relationship changes, body image changes, menopause symptoms, availability of sexual counseling, and availability of hormone replacement therapy); the amount of information they would have liked on the 9 specific issues; and whether they believed they would have changed their mind about the operation had they received different information pre-operatively. In addition, the questionnaire contained open-ended questions regarding additional information they would have liked about pre-operative discussions with women who are considering RRSO. The participants had completed the Female Sexual Function Index (FSFI) [11] within the 6 months prior to their participation in the current study.

Variables

The outcome of sexual function was measured by the Female Sexual Function Index (FSFI), which is a validated 19-Likert item measure [11]. A cut-off score has been psychometrically evaluated to discriminate between sexually functional and dysfunctional women, with those scoring a total FSFI of 26.55 being likely to have female sexual dysfunction (FSD) [12]. The FSFI assesses six domains of female sexual function; arousal, desire, pain, orgasm, lubrication and satisfaction. The combined score of the desire questions has been validated for the diagnosis of HSDD, with those scoring 5 or less having a high likelihood of HSDD [13]. We used these diagnostic cut-offs to determine FSD and HSDD diagnosis.

Bias

A potential source of bias in cross-sectional studies is non-response and attempts to minimize this in our study included mailing reminder letters 1 month after the initial invitation letter. Another source of bias is response bias although our high participation rate (60%) should mitigate this to some extent. The study design introduces recall bias, and does not allow for assessment of the actual rates of pre-operative discussions of sexuality.

Statistical analysis

All statistical analysis was performed using Stata 14.0 (StataCorp, 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP). Logistic regression was used to analyse data relating to the rates of FSD and HSDD. The participant’s recollection of discussions of each individual issue was categorized into a binary variable, as either “pre-operatively” or “other”. Similarly the patient satisfaction with the amount of information provided was categorized as either “wanting more” or “not wanting more”. The frequency with which discussions of specific issues were recalled pre-operatively and the number of issues participants would have liked more information about were the converted into continuous variables with possible ranges from 0-9 and analyzed using generalized linear models. No data on sexual function was available for two patients and these data points were treated as missing. The open-ended questions were coded by three members of the research team independently (PT,TJ,PC). From this analysis, themes were identified.

RESULTS

Of the 102 women contacted, 61 participated (60%) of which 59 (97%) had quantitative sexual function data available. Table 1 summarizes the participant characteristics.

The most common indication for RRSO was family history (48%), followed by breast cancer (21%). A genetic mutation had been confirmed in 28% of participants of whom 50% were BRCA2 positive, a quarter were BRCA1 positive, and a quarter had Lynch Syndrome (HNPPC). Other indications for surgery included Ashkenazi Jewish heritage (n=1).

Rates of recalled pre-operative discussions

A total of 17 participants (28%) did not recall any pre-operative discussions of sexuality issues, of which, 15 were post-
menopausal at the time of surgery (88%). On average, women recalled 1.6 topics being discussed pre-operatively (SD 1.9, range 0-8). The rates of discussion of specific topics are summarized in Table 2. Of the 72% of participants who recalled some discussion pre-operatively, the most common topics were menopause symptoms (43%) and HRT use (39%). Potential relationship changes (7%) and the availability of sexual counseling (8%) were the least common topics recalled.

Most women would have liked more information regarding vaginal dryness (61%) and decrease in libido (59%). Approximately half of participants would have liked more information regarding orgasm difficulty (51%), menopause (48%), dyspareunia (48%), and potential relationship changes (48%).

Factors associated with pre-operative discussion rates

There were 3 participants who were not in a relationship at the time of RRSO and all of these women did not recall any discussion of sexuality issues prior to surgery. Age at the time of operation was significantly associated with the number of topics discussed, with older women recalling less discussion of sexuality topics (p=0.005). Similarly, women who were post-menopausal at the time of surgery remembered significantly less discussion of sexuality than pre-menopausal women (p=0.023). However, the level of satisfaction with the amount of pre-operative discussion was similar between pre- and post-menopausal women (p=0.128). Time since operation was not associated with the number of topics recalled (p=0.318), nor was menopausal at the time of surgery remembered significantly associated with the rate of pre-operative discussion (p=0.548 and 0.281 respectively). However, women with FSD or HSDD did not desire more information pre-operatively (p=0.119 and 0.834 respectively). However, women with FSD or HSDD did report that they would have changed their mind were pre-menopausal at the time of surgery (71%).

Sexual function and recollections of discussions

Of the 59 women with quantitative sexual function data, 45 (76%) had female sexual dysfunction (FSD) and 43 (73%) had hypoactive sexual desire disorder (HSDD). Neither a diagnosis of FSD or HSDD was associated with the rate of pre-operative discussions recalled, controlling for age at operation (p=0.548 and 0.281 respectively). However, women with FSD or HSDD did not desire more information pre-operatively (p=0.119 and 0.834 respectively) when compared to women without FSD or HSDD.

Satisfaction with decision

Seven women (11%) reported that they would have changed their mind about undergoing the procedure if they had received information about the potential effects on their sexual function prior to surgery. All 6 of the women for whom sexual function data was available and who would have changed their mind, had FSD, and 4 had HSDD. The majority of those participants who reported that they would have changed their mind were pre-menopausal at the time of surgery (71%).

Open-ended questions

Fifty-eight women (95%) answered at least one of the open-ended questions. Thirteen women (21%) indicated they had no comments to make regarding pre-operative discussions. From the other 48 responses, 6 main themes were identified: alternative sources of information; timing of information; psychological impact and support; information regarding surgery; information regarding menopause management; and the detail of the information given.

Other sources of information

Access to additional sources of information was identified as an important aspect of pre-operative management by 21 women (34%). Several participants found it helpful to consult other health professionals for information, including a menopause clinic, menopause specialist, and women’s health physiotherapist. These participants advocated for routine pre-operative referral to a menopause clinic or allied health professional. Some participants reported searching online forums for information and advice, while others recommended access to written information in the form of a brochure.

Timing of information

The timing of the information received was reported an important factor for 9 women (15%). Several indicated that at the initial consultation, their focus was on cancer risk and survival rather than potential sexual issues after the surgery. These women felt that having a brochure to take home, or a follow-up appointment with an allied health professional a few weeks after the initial consultation was useful. Other women recommended an appointment with a menopause clinic or specialist 2-3 months after the surgery.

### Table 2: Rates of pre-operative discussion of topics recalled by participants.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Discussed Pre-Operatively</th>
<th>Discussed Post-Operatively</th>
<th>Never Discussed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Menopause</td>
<td>26 (43%)</td>
<td>9 (15%)</td>
<td>25 (41%)</td>
</tr>
<tr>
<td>Hormone Replacement Therapy</td>
<td>24 (39%)</td>
<td>9 (15%)</td>
<td>26 (43%)</td>
</tr>
<tr>
<td>Vaginal Dryness</td>
<td>13 (21%)</td>
<td>6 (10%)</td>
<td>42 (69%)</td>
</tr>
<tr>
<td>Change in Libido</td>
<td>12 (20%)</td>
<td>6 (10%)</td>
<td>43 (70%)</td>
</tr>
<tr>
<td>Dyspareunia</td>
<td>7 (11%)</td>
<td>8 (13%)</td>
<td>46 (75%)</td>
</tr>
<tr>
<td>Orgasm Difficulty</td>
<td>6 (10%)</td>
<td>3 (5%)</td>
<td>52 (85%)</td>
</tr>
<tr>
<td>Body Image</td>
<td>6 (10%)</td>
<td>4 (7%)</td>
<td>51 (84%)</td>
</tr>
<tr>
<td>Availability of Sexual Counselling</td>
<td>5 (8%)</td>
<td>4 (7%)</td>
<td>51 (84%)</td>
</tr>
<tr>
<td>Relationship Changes</td>
<td>4 (7%)</td>
<td>1 (2%)</td>
<td>56 (92%)</td>
</tr>
</tbody>
</table>

Sum of percentages may not equal 100 due to rounding or missing data.
Psychological impact

Recognition of the psychological impact of RRSO and the desire for psychological support was highlighted by 13 women (21%). The importance of having the clinician acknowledge and validate the psychological difficulty of the decision was expressed by many participants.

Surgical information

Detailed surgery-specific information was identified by 10 women (16%) as being important in the pre-operative discussion. Specifically, women indicated they had not anticipated the level of pain or time to recovery after the surgery.

Menopause management

Menopause management and thorough discussion of treatment options, including hormone replacement therapy risks and benefits was highlighted by 8 women (13%). These participants also recommended a referral to a menopause clinic or another specialist prior to surgery, to discuss these options in depth.

Detail of information

Eleven women (18%) indicated they would have liked a greater amount of detail in the information that they received pre-operatively. Several participants indicated that they were informed of general risks, rather than the specific symptoms which they might experience.

DISCUSSION

Several studies have reported that RRSO can have a significant negative impact on a woman’s sexual function [6-9] and that patients would like to receive more counseling about such issues prior to their surgery [10,14,15]. Whilst many women would value the opportunity to discuss sexual issues with a healthcare professional [14,16,17], patients’ recollections of such discussions appear to be low [14]. In the current study, 28% of participants did not recall any pre-operative discussion of sexual or menopausal issues, which is an improvement from the 60-80% rate reported in other studies [14,18]. In this study, older women were less likely than younger women to recall a pre-operative discussion of sexual issues (p=0.005). Similarly, women who were post-menopausal at the time of operation also reported lower rates of sexuality discussion (p=0.023). As the actual rates of sexuality discussion amongst this cohort is unknown, the difference between the age groups may be due to a variety of factors, including clinicians being less inclined to discuss sexuality with older women, the bias of older women in recalling such a discussion, or older women’s preference to not discuss sexuality with their doctor. To the best of our knowledge, this is the first study to report a difference in the rates of sexuality discussions amongst age groups of women undergoing RRSO. However, this study also found that pre- and post-menopausal women reported similar levels of satisfaction with the amount of information they received (p=0.128), suggesting that the topics discussed by clinicians pre-operatively were reflective of patient preference for information, regardless of the reason for the lower rates of discussion. Despite only a minority of participants recalling pre-operative discussions of sexual issues, only 11% (n=7) of participants indicated they would have changed their mind about having the surgery if they had received more information pre-operatively. This is consistent the findings of Madalinska et al., who reported a 14% rate of decision regret after RRSO [19].

Several themes were identified which may improve the counseling of women who are considering RRSO. The most common theme was the ability to access additional sources of information (n=21, 34%), in particular, access to written information in the form of an internet website or printed brochures was recommended by participants, which is consistent with the findings of other studies [14,20,21]. In addition to written information, participants felt that a routine pre-operative referral to a menopause clinic/specialist or allied health professional to discuss the potential sexual effects of the operation would be helpful. The timing of provision of information was also identified as an issue (n=9, 15%), with several women indicating that they felt overwhelmed with information regarding cancer risk and survival at their initial consultation. Whilst the importance of discussing the potential sexual consequences of RRSO prior to surgery, has been highlighted in the literature [10,14], the provision of such information at the initial consultation may not be optimal as the discussion of cancer risk may overshadow other topics. Several participants advocated for a follow-up appointment 2-3 weeks after the initial consultation, which allows more time for women to process their decision and to consider other potential consequences of the surgery. The recommendation to allow sufficient time to process information may also relate to the psychological aspect of the decision to undergo RRSO, the impact of which was highlighted by 21% (n=13) of participants. Suggestions made by participants to address this included access to a counselor or peer-support group pre-operatively, as well as the importance of having the clinician acknowledge the psychological and emotional magnitude of the procedure. With regard to specific topics, participants identified surgical detail (n=10, 16%) and menopause symptom treatment options (n=8, 13%) as areas in which they would have liked to receive more information. Overall, 18% (n=11) of participants recommended providing greater detail when giving information pre-operatively.

Limitations

The limitations of this study include the self-reporting questionnaire, which relies on participant recollections of information given up to 6 years previously, which may introduce significant recall bias. The study design relies on patient recall, and does not allow the actual rates of pre-operative discussion of sexuality to be determined. A recent survey of Gynaecologic Oncologists found that 61% of clinicians report always discussing sexuality [22], however the rates of sexuality discussions occurring amongst the study cohort is unknown. There is also a potential for response bias, although the high response rate (60%) should minimize this. This study was performed at a single private institution in Western Australia with participants recruited from the practices of three gynaecologic oncologists and hence the generalize ability of our results may be limited.

Conclusion and implications for clinical practice

In this study 28% of participants did not recall any information...
being given pre-operatively about the potential impact of the procedure on their sexual function. Older women were less likely to recall any discussion of these issues. There was no association found between recollection of pre-operative discussions about sexuality and current sexual function. Additional sources of information including referral to a menopause clinic and allied health professionals, internet websites and printed brochures were highlighted by participants as important components of pre-operative counseling. It is essential for healthcare professionals to acknowledge the psychological impact of RRSO and to allow women sufficient time to process their decision.

ACKNOWLEDGEMENTS

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study.

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REFERENCES