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What information do healthcare professionals need to inform premenopausal women about risk-reducing salpingo-oophorectomy?

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Abstract

Objective: The aim of this study was to identify the unmet information needs of healthcare professionals managing risk-reducing bilateral salpingo-oophorectomy (RRBSO) in premenopausal women.

Methods: A cross-sectional survey of healthcare professionals managing high-risk women in Victoria, Australia. Questions included roles and responsibilities around RRBSO, perceived barriers to uptake of RRBSO, and unmet information needs.

Results: One hundred eighteen healthcare professionals across 10 different disciplines and specialties were approached to participate, of whom 47 completed the survey. Most respondents were genetic counselors (47%) or nurses (19%) and all worked in the public health system. Almost all (81%) provided information about RRBSO, but there was considerable uncertainty about who was responsible for making decisions with high-risk women about RRBSO. Most (85%) were ''quite a bit'' or ''extremely'' confident about informing high-risk women about ovarian cancer risk reduction from RRBSO and the surgical procedure (47%), but only one-third were ''quite a bit'' or ''extremely'' confident about discussing (36%) or managing (31%) surgical menopause. Furthermore, surgical menopause was considered the main barrier (88%, ''quite a bit'' or ''extremely'') to RRBSO. Most healthcare professionals (78%) wanted more information and resources about surgical menopause for high-risk women.

Conclusions: There is uncertainty around the roles and responsibilities of healthcare professionals managing high-risk women around RRBSO. Surgical menopause is perceived as a major barrier to RRBSO and healthcare professionals lack confidence in managing this outcome.

Key Words: BRCA mutation – High-risk women – Risk-reducing bilateral salpingo-oophorectomy – Surgical menopause.

***Video Summary*:** http://links.lww.com/MENO/A477.

As genetic testing for hereditary cancers gains wider utilization, more women are being identified as being of high-risk for ovarian cancer and recommended to undergo risk-reducing surgery.[1] The largest population of high-risk women are those with germline mutations in the BRCA1 or BRCA2 genes where lifetime risk of ovarian cancer is around 44% for BRCA1 mutation carriers and 17% for BRCA2 mutation carriers, compared with around 1.4% for the general population.[2] Ovarian cancer carries a poor prognosis and there is currently no effective screening strategy to detect early stage disease. Only risk-reducing bilateral salpingo-oophorectomy (RRBSO) has been shown to reduce ovarian cancer deaths.[3] If performed within the recommended age ranges, RRBSO reduces ovarian cancer mortality by 95% and overall mortality by 76%.[4,5] The recommended age for RRBSO varies between countries and according to gene mutation and family history. In Australia, current guidelines recommended RRBSO by age 40 years in BRCA1 mutation

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carriers and by age 45 years in BRCA2 mutation carriers (www.eviq.org.au). Because menopause generally occurs at around age 50, RRBSO at the recommended age will generally lead to surgical menopause.[6]

Surgical menopause carries implications for short- and long-term physical and emotional health, and RRBSO in premenopausal women generally requires a multidisciplinary approach.[6] The type and range of healthcare professionals involved will vary between health systems and availability, but will commonly include genetic counselors and clinical geneticists, gynecological oncologists, and allied health specialists. Currently, the roles and responsibilities of these healthcare providers in managing women pre- and post-RRBSO are not clearly defined. Also, it is uncertain whether high-risk women and healthcare professionals feel fully informed about the potential noncancer consequences of bilateral oophorectomy in premenopausal women. To better support healthcare professionals and optimize care for high-risk women, we surveyed healthcare providers caring for high-risk women to determine their understanding of roles and responsibilities around RRBSO, knowledge about the cancer and noncancer consequences, perceived barriers and facilitators to timely uptake of RRBSO by patients, and unmet needs for information and resources.

METHODS

A cross-sectional survey was carried out of healthcare professionals managing high-risk women across the state of Victoria, Australia. Participants were identified by study steering committee members and heads of units/departments at three public hospitals (the Royal Women's Hospital, the Peter MacCallum Cancer Centre and the Royal Melbourne Hospital, Victoria, Australia). Additional participants were identified with chain referral (snowball) sampling, a convenience sampling technique to study rare and difficult-to-reach populations.[7] Inclusion criteria were healthcare professionals managing women at high inherited risk of ovarian cancer. In a parallel study, we have directly asked high-risk women about unmet information needs and barriers to uptake of RRBSO.[8]

MEASURES

An online questionnaire was developed by clinicians and researchers working with high-risk women and in collaboration with patients including demographic details (speciality, workplace, location of practice), perceived responsibilities of healthcare professionals for counseling, decision-making, and performing RRBSO. Participants were asked to rate their perceived level of knowledge about the consequences of premenopausal RRBSO for ovarian cancer risk, the surgical procedure and recovery, and the noncancer consequences of RRBSO in premenopausal women. Participants were asked to rate what they perceived to be the most common concerns around RRBSO for high-risk women from a list, including fertility, timing of surgery, menopausal symptoms, the surgical procedure, recovery, and ''change in sense of self'' or other (as free text). Participants were also asked to rate the degree to which they believed reasons influenced women not to have an RRBSO at the recommended, evidence-based age, including lack of understanding about cancer risk reduction, complexity of the surgery, treatable nature of ovarian cancer, concerns about surgical menopause, and other potential physical and psychological barriers. Three domains (knowledge, common symptoms, and barriers) were assessed using 5-point Likert-type response options from ''not at all'' to ''extremely.'' Participants were asked whether they provided women with any written material or other resources about RRBSO and whether they referred high-risk women to other specialists or services. To identify unmet information needs, respondents were asked what additional resources would assist them to support high-risk women making an informed decision about RRBSO. The questionnaire was piloted in a group of 10 high-risk women to ensure that the individual questions were clear and comprehensible and that the content was acceptable to patients.

DATA ANALYSIS

Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Melbourne.[9] REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies. Survey data were exported to Stata 15.1 (StataCorp, 2017, College Station, TX) for analysis. Categorical variables were summarized with frequencies and proportions. To rank the frequency of responses to provider knowledge, patient concern, and patient barrier items, Likert-type items were binarized (''extremely'' or ''quite a bit'' vs ''moderately,'' ''a little bit'' or ''not at all'').

ETHICAL CONSIDERATIONS

Ethical approval for the study was granted by the Human Research Ethics Committee of the Peter McCallum Cancer Centre (17/176). Data collection and storage adhered to the principles set by the Australian National Health and Medical Research Council (https://nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018).

RESULTS

One hundred eighteen healthcare professionals were approached, of whom 47 agreed to participate (40%). All respondents worked in the public health service and 10 (21%) also worked in the private health system. The largest professional group were genetic counselors (47%) followed by nurses (19%) and medical oncologists (11%). The remaining participants were psychologists (6%), breast/general surgeons (4%), gynecological oncologists ($n = 2$), and one each of gynecologist, trainee oncologist and geneticist, GP, and a gastroenterologist working in family cancer. Most respondents worked at the Familial Cancer Centre (62%), with the remaining based at a breast clinic (10%), gynecological oncology service (10%), in clinical genetics (6%), menopause and cancer service (4%), or ''other'' services (6%).

TABLE 1. *Self-reported level of knowledge of healthcare professionals managing high-risk women to counsel patients in the following areas, n (%)*

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Ovarian cancer risk reduction	1 (2.1)	0 (0)	6 (12.8)	22 (46.8)	18 (38.3)
Surgical procedure and recovery	1 (2.1)	12 (25.5)	12 (25.5)	13 (27.7)	9 (19.1)
Noncancer consequences	1 (2.1)	7 (14.9)	22 (46.8)	8 (17.0)	9 (19.1)
Management after surgical menopause	5 (10.6)	11 (23.4)	17 (36.2)	9 (19.1)	5 (10.6)

Most participants (77%) considered that providing advice about RRBSO was part of their professional responsibility. Of the 11 (23%) who did not consider this to be part of their remit, 5 were genetic counselors, 3 nurses, 2 psychologists, and 1 gynecologist. There was considerable variability and lack of clarity about roles and responsibilities for decision-making about RRBSO. Specifically, almost all (91%) thought the gynecological oncologist was responsible for decision-making with patients, but 62% also thought that a gynecologist, 74% geneticist or 77% genetic counselor, 53% breast or general surgeon, 25% GP, 28% nurse, or 8.5% ''other'' healthcare professionals, including a gastroenterologist, ''anyone who is trained,'' or medical oncologist, should be involved in decision-making.

Most respondents (89%) believed that a gynecological oncologist should perform the RRBSO or a gynecologist within a multidisciplinary team (57%). Only 4% believed that ''any gynecologist'' should perform risk reducing RRBSO.

When asked about their perceived level of knowledge in counseling high-risk women about the consequences of RRBSO (Table 1), 85% reported that they were ''extremely'' or ''quite a bit'' confident about ovarian cancer risk reduction and around half (47%) about the surgical procedure. Only one-third of respondents (36%) were, however, confident advising patients about surgical menopause following RRBSO or managing the symptoms of surgical menopause (30%).

When asked what they understood to be the main barriers to RRBSO for high-risk women (Table 2), the most frequent response (88%, ''extremely'' or ''quite a bit'') was menopausal symptoms, followed by decision-making around timing of the surgery (55%), fertility (35%), the surgical procedure (34%), change in sense of self (23%), and recovery (13%). Specific comments included patient concerns about ''rapid onset of menopausal symptoms'' and changes in their ''sense of self, femininity, sexuality, and attractiveness.''

Overall, the main perceived reason that women did not have an RRBSO at the recommended age was concerns about surgical menopause (71%, ''extremely'' or ''quite a bit''), followed by physical changes due to oophorectomy (49%) and not wanting to think about it (44%) (Table 3). Lack of understanding about cancer risk reduction following RRBSO and concerns about the operation itself were not considered to be major barriers to RRBSO. Competing demands, including work and family, were cited as ''other'' barriers to RRBSO.

Around half the respondents (51%) provided high-risk women with written resources about RRBSO. The source and content of this information, however, varied considerably, with more than 10 different sources mentioned. Almost all participants (91%) made additional referrals for high-risk women considering RRBSO to ''other healthcare professionals,'' but there was no clear coordination or pathway to direct these referrals. Around one-third (28%) referred high-risk women to a multidisciplinary service for managing menopausal symptoms after cancer and surgical menopause in high-risk women which is available in Australia.[10-12] Most respondents (68%) wanted more resources for high-risk women and mentioned (in free text) that decision aids previously developed for this purpose were now outdated because they offered the option of screening for ovarian cancer.[13] Specifically, respondents wanted more resources about the management of surgical menopause, optimization of long-term health (bone and cardiac disease), the use of systemic menopausal hormone therapy (HT) in high-risk women, and access to multidisciplinary care to manage these issues.

DISCUSSION

Around 1 in 350 women is at high inherited risk of ovarian cancer. Most commonly, this is due to inherited mutations in BCRA genes, affecting around 1 in 400 women[14] or Lynch syndrome, affecting around 1 in 280 women.[15] Increasing access to genetic testing means that more women are identified at high-risk for ovarian cancer. The only intervention shown to reduce ovarian cancer deaths in these women is RRBSO. The decision to undergo RRBSO carries short- and long-term health implications for premenopausal women and

TABLE 2. *Healthcare professionals' perceived ''most common concerns'' about RRBSO for high-risk women, n (%)*

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Fertility	6 (12.8)	16 (34.0)	9 (19.1)	13 (27.7)	3 (6.4)
Menopause	0 (0)	1 (2.1)	5 (10.6)	28 (59.6)	13 (27.7)
The surgery	1 (2.1)	9 (19.1)	21 (44.7)	16 (34.0)	0 (0)
Recovery	1 (2.1)	17 (36.2)	23 (48.9)	6 (12.8)	0 (0)
Change in sense of self	2 (4.3)	21 (44.7)	13 (27.7)	9 (19.1)	2 (4.3)
Timing of surgery	0 (0)	7 (14.9)	14 (29.8)	18 (38.3)	8 (17.0)
Other ($n = 7$)	—	1 (2.1)	4 (8.5)	1 (2.1)	1 (2.1)

RRBSO, risk-reducing bilateral salpingo-oophorectomy.

TABLE 3. *Healthcare professionals' perceived reasons for high-risk women declining or deferring RRBSO, n (%)*

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Lack of understanding about cancer risk reduction	15 (33.3)	19 (42.2)	8 (17.8)	3 (6.7)	0 (0)
Perceived complexity of the surgery and recovery	3 (6.7)	22 (48.9)	13 (28.9)	7 (15.6)	0 (0)
Belief in the treatable nature of ovarian cancer	21 (46.7)	15 (33.3)	9 (20.0)	0 (0)	0 (0)
Not wanting to think about it	7 (15.6)	18 (40.0)	9 (20.0)	17 (37.8)	3 (6.7)
Concerns about surgical menopause	0 (0)	4 (8.9)	9 (20.0)	24 (53.3)	8 (17.8)
Concerns about potential changes to their body	0 (0)	15 (33.3)	8 (17.8)	18 (40.0)	4 (8.9)
Other ($n = 13$)	1 (2.2)	2 (4.4)	5 (11.1)	4 (8.9)	1 (2.2)

RRBSO, risk-reducing bilateral salpingo-oophorectomy.

commonly includes several specialist services. Women with deleterious gene mutations conferring an increased risk of ovarian cancer have a lifetime cancer risk of up to 40%.[2] Despite this poor prognosis and international consensus that RRBSO is highly effective in reducing diagnosis and death from ovarian cancer in high-risk women,[5] uptake of RRBSO varies considerably worldwide from 17% to 89%.[16] In Australia, uptake of RRBSO has increased from 30% in 2006[17] to 38% in 2013[18] and 72% in 2018,[19] potentially reflecting increased media attention and changes in national guidelines which advise against ovarian cancer screening (www.eviq.org.au). Increased use of minimally invasive techniques, such as laparoscopy for RRBSO, may also have increased uptake.[19]

Our findings demonstrate that a wide range of healthcare professionals and clinical services are involved in the management of high-risk women. Although multidisciplinary care is the optimal approach for clinical services in cancer, our data suggest a lack of clarity around roles and responsibilities between healthcare professionals involved in caring for high-risk women. In particular, it is unclear who is actually responsible for making decisions with patients about whether and when to proceed with RRBSO. Although most healthcare professionals surveyed made referrals to other specialist services, there was no clear referral pathway, suggesting that high-risk women might be offered multiple medical appointments before proceeding with RRBSO. Many high-risk women are managing competing commitments with work and family, and it is not surprising that ''timing of surgery'' was a barrier to RRBSO. In Israel, where the prevalence of BRCA gene mutations is higher than many other settings, a multidisciplinary service offering co-located services, including medical oncologists, breast surgeons, gynecologists, plastic surgeons, and psycho-oncologists, demonstrated high uptake of RRBSO (over 90%).[20] Ongoing management of symptoms and prevention of chronic disease after surgical menopause were, however, not addressed in this model. Also, this service did not necessarily lead to timely uptake of RRBSO and 7.2% developed new cancers despite being under specialist review.

Public awareness and identification of high-risk women have focused on cancer risk reduction.[21] Our data suggest that this health promotion message has been effective and healthcare professionals are confident about advising high-risk women how RRBSO will reduce their ovarian cancer risk. They were, however, much less confident about providing information and managing noncancer outcomes. Current guidelines advise RRBSO by age 45 which will generally lead to surgical menopause.[6] Surgical menopause confers short-term risks of menopausal symptoms which may be more severe than those experienced at natural menopause,[22] sexual dysfunction which may be difficult to manage.[23,24] In the long term, surgical menopause may increase the risk of cardiovascular disease, dementia, depression, and osteoporotic fracture, and HT may be protective.[22] The risk versus benefits of premenopausal oophorectomy in high-risk women are, however, likely to differ from the general population because RRBSO substantially reduces risk of death from cancer and increases overall survival.[3]

Limited prospective data on RRBSO in premenopausal women suggest that vasomotor symptoms, sexual dysfunction, and discomfort during sexual activity are common and not fully resolved by systemic HT.[6,25] Gene mutation testing will reduce morbidity and mortality from cancer only in those patients who engage in risk-reducing strategies.[5] Our findings suggest that concerns about surgical menopause deter women from RRBSO and that healthcare professionals feel poorly equipped to manage these concerns or their clinical consequences.

High-risk women considering RRBSO to reduce their cancer risk should reasonably expect a normal quality of life after surgery. Estrogen-containing HT is currently the most effective treatment for menopausal symptoms and reduces the risk of fracture.[26] High-risk women who do not have contraindications should be encouraged to take estrogen after premenopausal RRBSO. HT is thought to be safe for high-risk women who do not have a personal history of breast cancer.[27,28] Uptake of HT after RRBSO is, however, generally low.[28,29] In addition, prospective and cross-sectional data suggest that menopausal symptoms and sexual dysfunction persist.[25,30] Recommendations and advice about HT after RRBSO may relate to the knowledge and experience of the healthcare professional.[19] Specifically, gynecologists may be more likely to recommend HT than other healthcare professionals.[19] Use of HT in the general population has declined internationally after concerns about safety, particularly the increased risk of breast cancer.[31] Although the risk versus benefit of systemic HT is likely to be different in younger menopausal women,[28] our data suggest that healthcare professionals focused on cancer risk reduction may not be confident managing the long-term consequences of surgical menopause including HT use.

The optimum model of care for high-risk women is not yet established. Although multidisciplinary clinics may be more convenient for patients, they can be challenging for health service providers. Similarly, although shared decision-making and supporting patient choice may be optimal in other health settings, this approach may not be ideal for high-risk women. Several studies have demonstrated that providing options for risk reduction reduces uptake of RRBSO.[19] When counseling for RRBSO is very directive and alternative options (such as screening) are not offered, the uptake of RRBSO at the recommended age is substantially increased.[32]

Healthcare professionals in this study wanted more resources to support women making informed choices about RRBSO. Decision aids are the optimal approach to providing personalized information and decisional support[33] and a new decision aid for RRBSO is under development.[34] Decision aids are, however, best suited to circumstances where there is no right or wrong option and where patient values may influence choices. The decision aid under development is comparing RRBSO with salpingectomy alone for high-risk women.[35] Salpingectomy alone has, however, not been shown to reduce ovarian cancer risk for high-risk women and is not currently recommended in practice guidelines (www.eviq.com.au).

It is neither cost-effective nor patient-centered to minimize cancer risk without optimizing other aspects of physical and emotional health after RRBSO. For women navigating these complex systems and for healthcare professionals providing comprehensive care between different specialists, we have established a dedicated multidisciplinary service for high-risk women and cancer patients in Australia which also manages surgical menopause and optimization of long-term health for high-risk women.[10-12] The service is staffed by specialists in menopause, endocrinology, and sexual function. High-risk women considering RRBSO are reviewed before surgery to provide information about the short and long-term consequences of surgical menopause and to make an individualized care plan for the management of menopausal symptoms after RRBSO. This approach has been shown to increase uptake of risk-reducing surgery.[36] The service also provides a platform for the prospective measurement of noncancer outcomes following RRBSO[11,37] and ensures that women are fully informed about likely health outcomes and optimization of long-term health.

Strengths of this study include the wide range of healthcare professionals sampled and specific questioning about referral pathways, specialist knowledge, practices, and beliefs. Limitations include small sample size, nonprobabilistic sampling method, and (potentially) lack of representation from other healthcare professionals involved in the care of high-risk women. Counseling for high-risk women and risk-reducing surgery is free under the Australian healthcare system, although some women choose to be managed in the private health system. Cost may be a barrier to uptake that was not addressed in our study, although time away from work was a concern. We have used the information collected from high-risk women and from their treating healthcare professionals to inform the development of new information resources for high-risk women and healthcare professionals addressing unmet needs.

Limitations include small sample size and only 40% participation from eligible healthcare professionals—no information was collected about those who declined to participate. Uncertainty about the management of surgical menopause may have motivated healthcare professionals to participate in this study. Participants were from a single city (Melbourne, Victoria) and may not be applicable to other centers or healthcare settings. Our study focused on RRBSO and did not discuss risk-reducing bilateral mastectomy.

CONCLUSIONS

This survey of healthcare professionals managing high-risk women identified uncertainty about roles and responsibilities around decision-making for RRBSO and inconsistent pathways for referral. Barriers to RRBSO included concerns about surgical menopause and timing of the surgery. Healthcare professionals felt poorly equipped to counsel women about surgical menopause or to manage the symptoms. There is an unmet need for targeted clinical services and information resources to manage the long-term consequences of RRBSO in premenopausal women.

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