Discussing Sexuality With Women Considering Risk-Reducing Salpingo-oophorectomy

An International Survey of Current Practice in Gynecologic Oncology

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Objective: To determine how frequently gynecologic oncologists discuss sexuality with women considering risk-reducing salpingo-oophorectomy. Secondary objectives were to assess the availability of resources, and the barriers to discussing sexuality.

Methods: Members of the Australian Society of Gynaecologic Oncologists, International Gynecologic Cancer Society, and Society of Gynecologic Oncology were invited to complete an online survey. Questions addressed frequency of, and barriers to, discussing sexuality, and availability of resources related to sexual issues.

Results: Three hundred eighty-eight physicians in 43 countries responded from 4,006 email invitations (9.7%). Ninety-one percent reported discussing sexuality preoperatively, and 61% discuss it with every patient. Factors associated with higher rates of discussion were female sex ($P = 0.020$), higher level of training ($P = 0.003$), time in practice ($P = 0.003$), and consulting more risk-reducing salpingo-oophorectomy patients per month ($P = 0.006$). Commonly discussed issues were vasomotor menopausal symptoms (91%) and vaginal dryness (85%). Eighty-eight percent of respondents believed that sexuality should be discussed preoperatively, and most felt that it is their responsibility (82%). Fear of causing distress was the most common barrier to discussing sexuality (49%). Twenty-four percent felt that they did not have adequate training to discuss sexual function.

Conclusions: Although most respondents believed that discussing sexuality should occur preoperatively, only 61% discuss this with every patient. Resources specifically relating to sexuality are limited. The most common barrier to discussing sexuality was fear of causing distress. Nearly one quarter of gynecologic oncologists felt inadequately trained to discuss sexual function.

Key Words: Risk-reducing salpingo-oophorectomy, Sexuality, Communication, Surgical menopause, BRCA1/2

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Women deemed to be at high risk for ovarian cancer are advised to undergo the prophylactic removal of their ovaries and fallopian tubes once childbearing is complete.[1] Although some women may opt for bilateral salpingectomy with delayed oophorectomy to preserve ovarian function, this has not been validated as an effective preventative measure for ovarian cancer and is currently not recommended.[2] In premenopausal women, the removal of ovaries and fallopian tubes in a procedure known as risk-reducing salpingo-oophorectomy (RRSO) will result in surgical menopause, and several studies have reported poor sexual outcomes after surgery.[3–7,12–15] A qualitative study by Brotto et al found that women who had a greater preoperative knowledge of the potential sexual consequences of RRSO experienced less subsequent sexual distress.[7] These women had independently sought information from the Internet, friends, or family, rather than counseling from their physician.[7] However, most women would prefer to receive this information from their surgeon.[8]

Despite the potential for improved sexual outcomes, and patients' preference to discuss these issues with their surgeon, the actual rates of discussions of sexuality by gynecologic oncologists in this setting seem to be low. Up to 70% to 100% of women undergoing RRSO report not receiving any counseling regarding the potential sexual adverse effects of the surgery.[7,8] Several barriers to gynecologic oncologists discussing sexual issues have been suggested. These include fear of causing patient distress, lack of experience and training, uncertainty regarding their responsibility to initiate discussion, insufficient time, and lack of knowledge and access to treatment resources.[9,10]

The aim of this study was to determine how frequently gynecologic oncologists discuss sexuality with women who are considering RRSO and to identify factors that may influence this frequency. Secondary objectives were to assess the perceived availability of resources specifically related to sexuality, and barriers to discussions about sexuality.

MATERIALS AND METHODS

Study Design

An online self-reporting survey of members of the Australian Society of Gynaecologic Oncologists (ASGO), International Gynecologic Cancer Society (IGCS), and Society of Gynecologic Oncology (SGO).

Setting

The study was undertaken through the Department of Gynecologic Oncology, St John of God Hospital Bendat Family Comprehensive Cancer Centre, Subiaco, Western Australia. This study was reviewed and granted ethics approval by the St John of God Healthcare Human Research Ethics Committee and the University Notre Dame Fremantle, Healthcare Human Research Ethics Committee. Data were collected between May 5 and November 5, 2015.

Participants

Permission to contact members was sought and granted from the Executive Committees of ASGO, IGCS and SGO. Emails were sent by either the individual societies, or by the researchers, to all members of ASGO, IGCS, and SGO, inviting them to complete the 10-question anonymous online survey. Initial invitation emails were followed by at least one reminder email 2 to 4 weeks later. Responses from members of these societies who were not gynecologic oncologists were excluded (eg, gynecologists, medical oncologists, pathologists, and researchers). Respondents who indicated that they do not consult women considering RRSO were also excluded.

Variables/Data Sources

The demographic data requested included sex, country of practice, the gynecologic oncology society with which they primarily aligned, level of training (gynecologic oncologist, trainee, or retired), and the year that they became a gynecologic oncologist. Respondents were asked to indicate how many women per month they consult regarding RRSO (none, less than 1 per month, 1–2 per month, 3–5 per month, and more than 5) and how frequently they discuss the potential sexual outcomes of this surgery preoperatively (never or only if the patient asks, less than 50% of the time, 50% of the time, more than 50% of the time, and always). Respondents were asked to indicate via multiple-choice questions which topics they discussed with women preoperatively (general reduction in sexual function, reduced libido, vaginal dryness, orgasm difficulty, reduced sexual satisfaction, dyspareunia, body image issues, impact on relationship, menopausal symptoms, other) and what resources specifically related to sexual issues were available to women considering RRSO (brochures, menopause clinic, nurse, sexual counselor, other). A Likert scale (completely agree, somewhat agree, unsure, somewhat disagree, and completely disagree) was used to assess barriers to discussing sexuality with RRSO patients. Potential barriers included causing distress to the patient, higher importance placed on discussing cancer risk reduction, inadequate time, inadequate training, belief that sexuality should not be discussed preoperatively, and belief that the discussion of sexuality is the responsibility of an allied health or other medical specialist.

Bias

Potential sources of bias in self-reporting surveys include nonresponse bias, and attempts to minimize this in our

study included reminder e-mails. Other sources of bias include response bias and recall bias.

Statistical Analysis

All statistical analysis was performed using the statistical software program Stata, version 14.0 (StataCorp. 2015. Stata Statistical Software: Release 14; StataCorp LP, College Station, TX). Based on their country, participants were assigned to a geographical region (Africa, Asia, Australia/New Zealand, Europe, Middle East, North America, and South America) for analysis. Responses regarding the discussion of specific topics and availability of resources were analyzed as binary variables, being either discussed/available or not discussed/not available and analyzed using logistic regression. The total number of topics discussed and resources available were calculated as continuous variables and analyzed using generalized linear models. The question regarding barriers to discussing sexuality used a Likert scale, and responses were converted to a 3-category variable: "agree", "disagree", and "unsure". Ordered logistic regression was used to analyze data relating to the barriers to discussing sexuality, with the Brant test used to ensure each model's parallel regression assumption was not violated.

RESULTS

Participants' Characteristics

Of the 4,006 ASGO, IGCS, and SGO members contacted, a total of 388 completed the survey, giving a minimum 9.7% response rate. However, the response rate is likely to be higher, as the exact proportion of overlap in membership between these societies is unknown. Thirty-six respondents were excluded because they were not gynecologic oncologists or never consulted patients considering RRSO.

Of the 352 gynecologic oncologists included in the study, 42 (12%) were primarily affiliated with ASGO, 80 (23%) were primarily affiliated with IGCS, and 203 (58%) were primarily affiliated with SGO. Despite ESGO not participating in the study, 27 respondents (8%) indicated they were primarily affiliated with ESGO. Owing to member overlap between the societies, the exact response rate from each society is unknown.

Table 1 summarizes the characteristics of the respondents. The gynecologic oncologists had been working as specialists for a mean (SD) of 15 (11) years (range, 0–45+). Respondents were currently working in 43 countries within 7 geographical regions.

TABLE 1. Characteristics of respondents

Factor	Number
Total	352
Society	
ASGO	12% (n = 42)
ESGO	8% (n = 27)
IGCS	23% (n = 80)
SGO	58% (n = 203)
Sex	
Female	45% (n = 160)
Male	54% (n = 190)
Unknown	1% (n = 2)
Position	
Gynecologic oncologist	87% (n = 306)
Resident/Fellow	9% (n = 32)
Retired gynecologic oncologist	4% (n = 14)
Region	
Africa	2% (n = 8)
Asia	9% (n = 32)
Australia/New Zealand	13% (n = 45)
Europe	9% (n = 30)
Middle East	1% (n = 5)
North America	62% (n = 217)
South America	3% (n = 10)
Unknown	1% (n = 5)

*Sum of percentages may not equal 100 owing to rounding.

Frequency of Discussing Sexuality

Overall, 91% of respondents reported sometimes initiating discussion of sexuality during RRSO consultations, with 61% stating they always have this discussion (Table 2). Factors associated with discussing sexuality more frequently included female sex ($P = 0.020$), level of training ($P = 0.003$), time in practice ($P = 0.003$), and a greater number of women consulted per month ($P = 0.006$).

North American respondents discuss sexuality preoperatively more frequently than those from Africa ($P = 0.030$), Australia/New Zealand ($P = 0.024$), Europe ($P = 0.036$), and South America ($P = 0.021$), regardless of level of training, sex, or number of women seen.

Topics Discussed

Overall, respondents discussed a mean (SD) of 4 (2.0) topics (range, 0–10) at the preoperative consultation, with vasomotor menopausal symptoms and vaginal dryness being the most commonly discussed issues (Table 3). No factors influenced the number of topics the respondents discussed.

Awareness of Resource Availability

Table 4 summarizes the respondents' awareness of information resources, which are available to their patients. The respondents were aware of a mean (SD) of 1.5 (1.1) (range, 0–5) resources, with those who discuss sexuality more frequently being aware of more resources ($P = 0.003$). Longer time in practice as a gynecologic oncologist was also associated with an awareness of more resources ($P = 0.002$). However, there were no geographic or sex ($P = 0.271$) differences in the number of resources the respondents were aware of.

Barriers to Discussions

Table 5 highlights responses to questions regarding potential barriers to discussing sexuality with women considering RRSO.

TABLE 2. Self-reported frequency of preoperative sexuality discussions in women considering RRSO

Frequency	Rate
Always	61% (n = 214)
Sometimes	31% (n = 108)
Never or only if asked	8% (n = 29)

Distress to Patient

Patient distress was the most commonly reported barrier to discussion, with 49% of the respondents believing that discussing sexuality might cause their patient distress. Geographical region was the only factor associated with likelihood to identify patient's distress as a barrier, with respondents practicing in Asia being most likely to feel that such discussions might cause distress compared to those in other regions (odds ratio [OR], 2.19; 95% confidence interval [CI], 1.04–4.63; $P = 0.039$).

More Important to Discuss Cancer Risk Reduction in Depth

The importance of discussing cancer risk in depth was identified as the second most common barrier to discussing sexuality preoperatively, with 43% of respondents agreeing this was an issue. Male respondents were more likely than female respondents to believe that discussing cancer risk was of greater importance than discussing sexuality (OR, 1.58; 95% CI, 1.03–2.44; $P = 0.038$). Similar to the concern of causing patient distress, respondents practicing in Asia were also more likely to believe that cancer risk discussions are more important than sexuality discussions preoperatively, regardless of sex (OR, 2.91; 95% CI, 1.35–6.30; $P = 0.007$). Respondents who agreed that sexuality discussions were not as important as cancer risk discussions were aware of fewer information resources available to their patients (OR, 0.80; 95% CI, 0.66–0.96; $P = 0.019$).

Inadequate Training

Nearly one quarter (24%) of respondents agreed that inadequate training was a barrier to discussing sexuality.

TABLE 3. Rates of discussion of specific topics

Issues	Rates of Discussion
Vasomotor menopausal symptoms	91% (n = 321)
Vaginal dryness	85% (n = 300)
Dyspareunia	56% (n = 198)
Reduced libido	55% (n = 195)
General reduction in sexual function	33% (n = 116)
Potential relationship changes	25% (n = 89)
Body image issues	23% (n = 81)
Reduced satisfaction	18% (n = 65)
Orgasm difficulty	11% (n = 39)
None	3% (n = 11)

TABLE 4. Rates of availability of resources

Resource	Availability
Brochures	41% (n = 146)
Nurse	39% (n = 136)
Menopause clinic	35% (n = 123)
Sexologist/Sexual counselor	30% (n = 106)
Other specialist	4% (n = 14)
Internet	2% (n = 8)
None	19% (n = 68)

Level of experience correlated with perceived lack of training as a barrier, with 34% of trainees agreeing that it was an issue, compared to 23% of gynecologic oncologists (OR, 2.14; 95% CI, 1.06–4.30; $P = 0.033$). Furthermore, for every additional year in practice as a gynecologic oncologist, respondents were 3% less likely to see inadequate training as a barrier (OR, 0.97; 95% CI, 0.95–0.99; $P = 0.021$).

Inadequate Time

Inadequate time was identified by more than a third of respondents (37%) as a barrier to discussing sexuality preoperatively. Time in practice as a gynecologic oncologist was the only factor associated with perceiving time as a barrier, with every additional year in practice resulting in a 4% reduction in likelihood of viewing time as a barrier (OR, 0.96; 95% CI, 0.94–0.99; $P = 0.001$).

Sexuality Should Not Be Discussed Preoperatively

Whereas 88% of respondents felt that they should be discussing sexuality preoperatively, only 61% always have the discussion. A small proportion (7%) felt that sexuality should not be discussed preoperatively, and those respondents discussed fewer issues with their patients (OR, 0.79; 95% CI, 0.65–0.95; $P = 0.013$) and were aware of fewer information resources (OR, 0.59; 95% CI, 0.41-0.83; $P = 0.002$).

Retired gynecologic oncologists were more likely to believe that sexuality should not be discussed preoperatively (OR, 3.80; 95% CI, 1.13–12.78; $P = 0.031$) as were respondents practicing in Asia (OR, 6.20; 95% CI, 2.46–15.63; $P \leq 0.001$), Europe (OR, 3.17; 95% CI, 1.13–8.90; $P = 0.029$), and South America (OR, 6.77; 95% CI, 1.53–29.99; $P = 0.012$). Despite women being more likely to discuss sexuality preoperatively, gender was not a significant factor in the belief that sexuality should not be discussed preoperatively ($P = 0.477$).

Responsibility of Allied Health/Another Specialist

Geographic region was the only significant factor in the belief that discussing sexuality is the responsibility of allied health or other specialists. Respondents in practice in Asia

TABLE 5. Responses to perceived barriers to sexuality discussions

Barrier	Agree	Disagree	Unsure
Discussion would cause distress	49% (n = 171)	42% (n = 148)	9% (n = 32)
More important to discuss cancer risk	43% (n = 150)	51% (n = 177)	5% (n = 19)
Inadequate time	37% (n = 129)	55% (n = 195)	8% (n = 28)
Inadequate training	24% (n = 85)	68% (n = 236)	8% (n = 27)
Should not be discussed at the initial consult	7% (n = 23)	88% (n = 307)	5% (n = 17)
Discussion is someone else's responsibility	10% (n = 33)	82% (n = 282)	8% (n = 27)

*Sum of percentages may not equal 100 owing to rounding.

were more likely to believe that discussing sexuality is not their responsibility (OR, 6.47; 95% CI, 2.94–14.25; $P \leq 0.001$), whereas those in North America were less likely than other geographic regions to hold this view (OR, 0.43; 95% CI, 0.24–0.75; $P = 0.003$). Respondents who did not believe that it is their responsibility to discuss sexuality were not more likely to have another specialist ($P = 0.336$), sexual counselor ($P = 0.453$), nurse ($P = 0.084$), or menopause clinic ($P = 0.054$) available to their patients.

DISCUSSION

Preoperative knowledge of the potential sexual sequelae of RRSO has been linked to improved outcomes, with the women having access to such preoperative information reporting fewer sexual issues after surgery.[7] However, despite evidence that most patients wish to discuss sexuality with their physicians,[11] actual rates of discussions recalled by patients are low.[7,8] In the current study, 91% of gynecologic oncologists reported at least sometimes discussing sexuality at the preoperative RRSO consultation. These findings differ markedly from the published 0% to 28% rate of discussions recalled by patients,[7,8] which may be due to recall and selection bias in these studies or response bias in the current study. However, several factors were identified in this study that were associated with a higher frequency of sexuality discussions preoperatively including higher level of training ($P = 0.003$), longer time in practice ($P = 0.003$), and greater numbers of consultations per month ($P = 0.006$). Furthermore, gender was also a significant factor in the frequency of sexuality discussions, with female respondents discussing sexuality more often than their male colleagues ($P = 0.020$). This difference may be due to male respondents feeling it was more important to discuss cancer risk in depth than discuss sexuality ($P = 0.038$). Despite this, the male respondents felt similarly to the female respondents in agreeing that sexuality should be discussed preoperatively and that it is the responsibility of the gynecologic oncologist to have this discussion. Overall, 88% of the gynecologic oncologists surveyed agreed that sexuality should be discussed preoperatively and 82% felt that it was their responsibility to have that discussion. However, only 61% report discussing sexuality with every patient, which may be due to several barriers to discussion identified in this study.

Previous studies have identified potential barriers to discussing sexuality including patient and physician embarrassment, focus on other issues, time constraints, inadequate training, a belief that sexuality should not be discussed, uncertainty about who should be responsible for discussing sexuality, and uncertainty regarding available treatment options for sexual issues.[9,10,16] In this study, agreement by respondents with any one of the barriers was associated with a lower frequency of sexuality discussion preoperatively. The most commonly perceived barrier was the belief that discussing sexuality would cause the patient distress (49%). Whereas cultural differences in the acceptability of discussing sexuality are important to consider, studies in western cultures indicate that patients wish to discuss sexuality with their doctor.[7,8,11,17,18] A study reported by Marwick in North American adults found that whereas 85% of people would discuss sexuality with their doctor, 68% believed that it would embarrass the physician.[11] In the current study, nearly half of respondents believed that discussing sexuality might distress patients, with the term distress potentially encompassing a variety of emotions, including anxiety and embarrassment. Thus, reciprocal fear of distressing the other party may be a significant barrier to open discussions about sexuality.

Another potential barrier to discussing sexuality is the importance placed on discussing other issues, such as cancer risk and the surgical procedure.[8,16] In the current study, 43% of respondents agreed that discussing cancer risk was more important than discussing sexuality preoperatively. However, this belief contrasts with the information needs expressed by women who have undergone RRSO, 59% of whom wished they had received more information regarding the effect of the surgery on their sex life, and 57% expressing a desire for more information on sexual counseling.[8] The need for gynecologic oncologists to prioritize topics discussed with patients preoperatively may be due to the time constraints often placed on physicians in busy health care systems.[9] In the current study, 37% of respondents felt that they had inadequate time to discuss sexuality, with junior gynecologic oncologists being more likely to view time as a barrier ($P = 0.001$). This may explain the findings that both time in practice and level of training were associated with frequency of sexuality discussions preoperatively ($P = 0.003$ for both). An alternative explanation for this may be that the junior physician has less confidence to initiate such discussions owing to inadequate

training. Almost one quarter of respondents identified inadequate training as a barrier to discussing sexuality, however, 34% of residents and fellows felt that they were inadequately trained compared to 23% of gynecologic oncologists. The importance of appropriate training in discussing and treating sexual issues in women has been highlighted.[19] There are several online resources available for physicians, and some of these are listed in Appendix A.

Another consideration when assessing barriers to sexuality discussions is the physician's awareness of available treatment options. Physician s may be hesitant to initiate the conversation if they feel they cannot offer patients treatment for issues they may disclose. In the current study, almost 1 in 5 respondents were not aware of any local resources that were available to specifically address sexual issues. Of interest, the number of available resources reported by respondents correlated with the frequency with which these physicians discuss sexuality (P = 0.003), indicating that awareness of resources may be a barrier to initiating sexuality discussions.

Limitations

Our study has several limitations including nonresponse. Low response rates are common in physician surveys, but nonresponse does not always equate to nonresponse error.[20] Outcomes may have also been subject to response bias, although it has been suggested that lower response rates in physician surveys are not associated with a higher likelihood of response bias.[21] However, the low response rate may limit the generalizability of these results. Self-reporting has the potential to introduce recall bias and information bias.

Conclusion and Implications for Clinical Practice

In this survey of gynecologic oncologists and trainees in 43 countries, 88% of respondents believed that sexuality should be discussed preoperatively with women considering RRSO. However, only 61% of the respondents actually discuss sexuality with every patient. Factors associated with higher rates of discussion about sexuality were female sex, level of training, and length of time in practice. An area for improvement identified by this study was training, with one quarter of respondents feeling inadequately trained to discuss sexuality with their patients. There are several online training courses designed to enhance physicians' skills in this area (Appendix A), and the ExPLISSIT model for sexual communication in the medical setting is a framework that may assist physicians to incorporate routine sexuality discussions into their practice.[22] Another area identified for improvement is awareness of available resources that specifically address sexual issues. Routine referral of patients to a sexual counselor or menopause clinic before RRSO surgery is recommended. This would be expected to improve the quality of information given to women who are considering this procedure.

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Appendix A. List of resources available to clinicians regarding the discussion and treatment of sexuality issues in women

Resource	Source	Summary	Address
PSGC Learning Modules	Cancer Australia	Learning modules and videos regarding the psychosexual care of women affected by gynecological cancers	http://modules.cancerlearning.gov.au/psgc/
ARHP Female Sexuality Handbook	Association of Reproductive Health Professionals (ARHP)	Handbook on female sexual health and wellbeing, including conversation starting and referrals	https://www.arhp.org/publications-and-resources/clinical-practice-tools/handbook-on-female-sexual-health-and-wellness
ACOG WEBTREATS: Sex and Sexuality	American Congress of Obstetricians and Gynecologists (ACOG)	List of resources available within the USA	http://www.acog.org/About-ACOG/ACOG-Departments/Resource-Center/WEBTREATS-Sex-and-Sexuality
ASHA Resources for Health Practitioners	American Sexual Health Association (ASHA)	Video and links to guides regarding sexual history taking	http://www.ashasexualhealth.org/healthcare-providers/sexual-health/
AASECT list of sexual therapists	American Association of Sexuality Educators, Counselors and Therapists (ASSECT)	List of US sexual therapists by state and city	http://www.aasect.org/referral-directory
Australian Society of Sexologists	Australian Society of Sexologists	Patient information and contact details for sexual therapists in Australia	http://societyaustraliansexologists.org.au