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Factors associated with deciding between risk-reducing salpingo-oophorectomy and ovarian cancer screening among high-risk women enrolled in GOG-0199: An NRG Oncology/ Gynecologic Oncology Group Study

Phuong L Mai, MD[1,*], **Marion Piedmonte, MA**[2], **Paul K Han, MD**[3], **Richard P Moser, PhD**[4], **Joan L Walker, MD**[5], **Gustavo Rodriguez, MD**[6], **John Boggess, MD**[7], **Thomas J Rutherford, MD**[8], **Oliver Zivanovic, MD, PhD**[9], **David E. Cohn, MD**[10], **J Tate Thigpen, MD**[11], **Robert M Wenham, MD**[12], **Michael L Friedlander, MD**[13], **Chad A Hamilton, MD**[14], **Jamie Bakkum-Gamez, MD**[15], **Alexander B Olawaiye, MD**[16], **Martee L Hensley, MD**[17], **Mark H Greene, MD**[18], **Helen Q Huang, MS**[2], and **Lari Wenzel, PhD**[19]

[1]Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, Rockville, MD 20852-9772; current address: University of Pittsburgh Medical Center, Magee Womens Hospital, Pittsburgh, PA 15213

[2]NRG Oncology, Statistical and Data Center, Roswell Park Cancer Institute, Buffalo, NY 14263

[3]Center for Outcomes Research and Evaluation, Maine Medical Center Research Institute, Portland, ME 04101

[4]Behavioral Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD 20850

[5]Stephenson Cancer Center, Department of Gynecologic Oncology, University of Oklahoma Health Sciences Center, Oklahoma City, OK 73104

[6]Division of Gynecologic Oncology, Department of Obstetrics and Gynecology, NorthShore University Health System, Evanston, IL 60201

[7]Gynecologic Oncology Program, University of North Carolina, Chapel Hill, NC 27514

[8]Gynecologic Oncology, Yale University School of Medicine; New Haven, CT 06520

[9]Director, Innovative Surgical Technology, Gynecology Service, Department of Surgery, Memorial Sloan Kettering Cancer Center, New York, NY 10022

[10]Division of Gynecologic Oncology, Ohio State University College of Medicine, Columbus, OH

Corresponding Author: Phuong L. Mai MD, MS, Cancer Genetics Program, Magee-Womens Hospital, 300 Halket St, Suite 1651 Pittsburgh, PA 15213 Voice: 412 641, 7449; Fax: 412 641 1132; maip@mail.magee.edu.

*Current affiliation for Dr. Mai is at Magee-Womens Hospital, Pittsburgh, PA.

Conflict of Interest

The authors wish to disclose that there are no conflicts of interest.

[11]Division of Medical Oncology, University of Mississippi Medical Center, Jackson, MS 39216

[12]Department of Gynecologic Oncology, Program of Chemical Biology and Molecular Medicine, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL 33612

[13]Professor of Medicine, Medical Oncology, The Prince of Wales Hospital, Randwick, NSW 2031 Australia

[14]Chief and Program Director, Gynecologic Cancer Center of Excellence, Walter Reed National Military Medical Center, Bethesda, MD 20889

[15]Department of GYN Surgery, Mayo Clinic, Rochester, MN 55905

[16]Department of Obstetrics, Gynecology and Reproductive Sciences, Magee-Women's Hospital of UPMC, University of Pittsburgh School of Medicine, Pittsburgh, PA 15143

[17]Gynecologic Medical Oncology Service, Memorial Sloan Kettering Cancer Center, Weill Cornell Medical College, New York, NY 10065

[18]Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, Rockville, MD 20852

[19]Center for Health Policy Research, University of California, Irvine, Irvine CA 92697

Abstract

Objectives—Women at increased genetic risk of ovarian cancer (OC) are recommended to have risk-reducing salpingo-oophorectomy (RRSO) after completion of reproductive planning. Effective screening has not been established, and novel screening modalities are being evaluated.

Methods—Participants chose either RRSO or a novel OC screening regimen (OCS) as their risk management option, and provided demographic and other data on *BRCA* mutation status, cancer worry, perceived intervention risks/benefits, perceived cancer risk, and quality-of-life at enrollment. We performed univariate and multivariate analyses to evaluate factors influencing decision between RRSO and OCS.

Results—Of 2,287 participants enrolled, 904 (40%) chose RRSO and 1,383 (60%) chose OCS. Compared with participants choosing OCS, participants choosing RRSO were older ($p<0.0001$), more likely to carry deleterious *BRCA1/2* mutations ($p<0.0001$), perceive RRSO as effective, be more concerned about surgical harms and OCS limitations, and report higher perceived OC risk and OC-related worry. OCS participants were more likely to perceive screening as effective, be more concerned about menopausal symptoms, infertility, and loss of femininity, and report better overall quality-of-life. Twenty-four percent of participants believed they would definitely develop OC, and half estimated their lifetime OC risk as >50%, both higher than objective risk estimates.

Conclusions—Cancer worry, *BRCA1/2* mutation status, and perceived intervention-related risks and benefits were associated with choosing between RRSO and OCS. Efforts to promote individualized, evidence-based, shared medical decision-making among high-risk women facing management choices should focus on conveying accurate OC risk estimates, clarifying the current understanding of intervention-related benefits and limitations, and addressing OC worry.

Introduction

BRCA1 and *BRCA2*, the two major breast/ovarian cancer susceptibility genes, are associated with significantly increased breast and ovarian cancer (OC) risk. Among *BRCA1/2* mutation carriers, risk-reducing salpingo-oophorectomy (RRSO) has been shown to reduce breast and ovarian/fallopian tube cancer incidence as well as cancer-specific and overall mortality, and is considered the most effective management option [1–3]. However, there remains a small risk of primary peritoneal carcinoma after RRSO [3, 4]. Moreover, RRSO in premenopausal *BRCA1/2* mutation carriers causes surgical menopause with both acute and potential long-term morbidity [5–9]. Nonetheless, most studies have shown limited to no adverse effects of RRSO on overall health-related quality of life (QOL) among high-risk women [5, 10–12].

Ovarian cancer screening (OCS) with periodic transvaginal ultrasound (TVUS) and serum CA-125 measurements has been offered to women with elevated OC risk; however, it has not been shown to be effective among high-risk women [13–16] and there is currently no safe and effective ovarian cancer screening test. Furthermore, OCS is associated with frequent false-positive screening test results and anxiety [17, 18]. More recently, the Risk of Ovarian Cancer Algorithm (ROCA), a novel screening strategy consisting of longitudinal CA-125 measurements analyzed by Bayesian modeling, followed by secondary screening with TVUS if indicated, has shown promise among average-risk [19], and high-risk women [20], with no clinically significant psychological morbidity among average-risk women undergoing repeat testing following abnormal screening tests [21]. At the time this study was carried out, the performance characteristics and psychological impact of this investigational screening strategy among increased risk women were not known.

RRSO and OCS differ in their outcomes, outcome-associated uncertainties, and potential short-term and long-term physical and psychological harms. The decision between these modalities has been shown to be influenced by individual women's demographic characteristics as well as personal preferences and values [11, 22–26].

Additional factors that may influence the choice between RRSO and OCS include perceptions of the potential benefits, harms, and uncertainties associated with alternative management options, key constructs in the ideal of shared decision-making (SDM) – a collaborative, deliberative process to make decisions that are well-informed, evidence based and consistent with patients' values [27–29]. Understanding which specific personal and psychological factors influence the choice between these interventions is essential in promoting well-informed risk management decisions.

The aim of the current study was to identify factors – including not only sociodemographic and clinical characteristics, but also perceptions and values related to OC risk and its management–associated with choosing between surgery and screening for OC risk management.

Materials and Methods

Study population

GOG-0199 is a multi-institution, international, prospective cohort study of women at increased familial/genetic risk of OC. Detailed eligibility criteria for GOG-0199 have been published previously [30]. In brief, women were eligible if they: (1) carried a deleterious *BRCA1/2* mutation or had a first-degree relative (FDR) or second-degree relative (SDR) with a mutation; (2) had a family history of at least two ovarian and/or breast cancers among the participant or her first- or second-degree relatives within the same lineage; (3) were of Ashkenazi Jewish ancestry and had a personal history of breast cancer, or had one FDR, or two SDRs, with breast and/or ovarian cancer; or 4) reported a family history of breast and/or ovarian cancer that conferred at least 20% probability of being a *BRCA* mutation carrier. Participants were at least 30 years of age, had no prior history of ovarian/fallopian tube/peritoneal cancer, and had at least one intact ovary. At enrollment, participants chose either RRSO or OCS with the ROCA algorithm [20].

The study opened in June 2003, and closed to accrual on November 3, 2006. Prior to undergoing the selected intervention, study participants completed a decision-making questionnaire relating to their risk management choice. Study participants enrolled prior to April 24, 2006 also completed the “Baseline Quality of Life Questionnaire” which contained a battery of QOL instruments and questions regarding perceived OC risk and OC worry. In this report, we first present the descriptive and decision-making data for the entire study population, and then present the data for the subset of participants who completed both the decision-making questionnaire and the baseline QOL questionnaire.

All subjects signed written informed consent (GOG Protocol 0199; NCI Protocol 02-C-0268; NCT-00043472).

Measures

Sociodemographic and Cancer History Information—We collected demographic information on age, race, menopausal status, marital status, education, self-reported *BRCA1* and *BRCA2* mutation status, personal history of breast and other cancers, and family history of breast cancer and OC. Although the mutation status of nearly all study participants was eventually confirmed on study, for the current analysis we considered the mutation status as reported by the subject at the time of study enrollment as the variable of interest, since this best reflected participants’ understanding of their mutation status at the time of decision-making.

Cancer- and Treatment-related Perceptions

Perceived efficacy of the intervention—Perceived efficacy was assessed using two items: (1) “Do you believe that removal of the ovaries and tubes is an effective way to lower your risk of ovarian cancer?” and (2) “Do you believe that screening is an effective way to detect ovarian cancer early enough that it can be treated effectively?” Responses include “Definitely no,” “Probably no,” “I am uncertain,” “Probably yes,” and “Definitely yes.”

Values regarding alternative choice outcomes—Patient values were measured by items assessing the extent to which a particular aspect of the surgical procedure or screening strategy influenced their decision, using a three-category Likert response scale: “Not at all,” “Some,” and “Very much.” These items focused on four domains: 1) *adverse effects associated with RRSO or OCS* (five items) 2) *financial costs associated with each option* (two items) 3) *life disruption from effect of the interventions* (two items) and 4) *effects of interventions on sexual and general well-being* (six items).

Perceptions regarding effect of family history on OC risk—Participants were asked to indicate whether they agreed (yes/no) with the following two statements: (1) “I have reached the same age at which other women in my family have developed cancer,” and (2) “If the cancer risk is inherited from my father's side of the family, my risk of developing cancer is lower than if it came from my mother's side of the family.”

Ovarian Cancer Risk Perception and Quality of Life Measurements

A separate questionnaire was completed at enrollment to assess overall QOL (SF-36), hormone related symptoms (FACT-ES), perceived lifetime OC risk and subjective certainty about their own risk estimate, and concerns about OC risk. Only participants (n=1,644) accrued prior to April 24, 2006 completed this questionnaire.

Perceived Lifetime Ovarian Cancer Risk—This item assessed a participant’s perceived risk of developing OC (“What do you think your chances of getting ovarian cancer in your lifetime are on a scale from 0 to 100%, where 0 is no chance of getting it and 100% means you will definitely get it?”)

Perceived Uncertainty about Ovarian Cancer Risk—Participants were then asked how certain she was about the risk estimate (“How certain are you about the opinions you just offered regarding your chances of getting ovarian cancer?”) Response options included “not at all,” “somewhat,” “fairly,” and “very” certain.

Ovarian Cancer-Related Worry—These 3 items, adapted from the Lerman Cancer Worry Scale [31], measure worry related to OC risk and how often it affects the participant’s mood and daily activities. Responses were grouped into low worry (“not at all or rarely”, plus “sometimes”) and high worry (“often”, plus “almost all the time”).

Medical Outcome Study Short Form-36 (MOS SF-36)—The MOS SF-36 was used to measure overall QOL. It is a validated self-reported set of questions containing eight subscales - general health perceptions, physical functioning, roles limitations due to physical problems, roles limitations due to emotional problems, bodily pain, vitality, social functioning, and general mental health - which are summarized into the Physical Component Score (PCS) and the Mental Component Scores (MCS) [32]. Factor analyses with correlated rotation (oblique promax rotation) were conducted to obtain the scoring coefficients for the PCS and MCS [32]. Higher scores indicated better QOL.

The Functional Assessment of Cancer Therapy–Endocrine Subscale (FACT-ES)—The FACTES is a validated 18-item scale specifically designed to measure hormone-

related symptoms [33]. Participants reported on menopausal and sexual symptoms over the 7 days prior to filling out the instrument. An overall total score was calculated by summing the individual score for each item (range 0–72). Higher scores indicated fewer bothersome menopausal symptoms.

Statistical Analyses—Sociodemographic characteristics, health-related factors, and perceived influence on decision-making, as well as perceived effect of family history on OC risk were compared between participants who chose RRSO or OCS, using chi-square and t-tests for individual categorical and continuous predictor variables, respectively.

Multivariable logistic regression with 'stepwise' model selection was used to explore the association between the choice of RRSO *versus* OCS and the potential influential factors. A significance level of 0.05 was set for both entering and removing variables from the regression model. Participants with ≥1 missing value for the independent variables were excluded from the multivariate logistic regression analysis.

Analyses of the association between risk management decision and QOL, cancer risk perception, and OC-related worry, in addition to the variables included in the multivariate logistic regression described above, were performed for participants from whom this information was collected (*i.e.,* those enrolled prior to April 26, 2006).

The PCS and MCS summary scores of the SF-36 were obtained by using the factor analyses with correlated rotation (oblique promax rotation) and were computed by multiplying each of the standardized subscale score by its respective scoring coefficient and summating the results over the eight subscales. The two summary scores were then rescaled to a normal distribution with mean of 50 and standard deviation of 10. Means, standard deviations, 95% confidence intervals (CI), and mean group differences, adjusted for age and menopausal status, were calculated for the FACT-ES scores. A step-wise multivariate logistic regression was carried out for this subset of participants, with the same variables as for the entire study population described above, and the addition of these QOL and cancer risk perception and worry variables.

All analyses were performed using the SAS software, version 9.3 (SAS Institute Inc., Cary, NC). P-values were not adjusted for multiple comparisons.

Results

Sociodemographic and Health Characteristics

Completed medical decision-making questionnaires were obtained from 2,287 study participants, of whom 904 (40%) chose RRSO, and 1,383 (60%) chose OCS at enrollment. Participants ranged in age from 30 to 83 (mean 47, SD 9.5 years), most were white (96%), married or living with a partner (76%), and had at least a college education (66%). Thirty-three percent reported being positive for a deleterious *BRCA* mutation, 39% were post-menopausal, 46% had a personal history of breast cancer, and 50% had a personal history of any cancer.

Women choosing RRSO were slightly older than those choosing OCS (median 47 *vs.* 46 years; p=0.01). More participants in the RRSO cohort were post-menopausal, married or living with a partner, self-reported *BRCA* mutation carriers, had a history of breast or any cancer, and had less than a college education (Table 1).

Perceived efficacy of RRSO and OCS

Ninety-eight percent of RRSO participants and 81.3% OCS participants responded that RRSO was "probably" or "definitely" effective in reducing OC risk (p<0.0001), while 29.7% and 65.5% in the RRSO and OCS groups, respectively, responded that OCS was "probably" or "definitely" effective in detecting cancer early enough to allow for effective treatment (p<0.001).

Values regarding alternative choice outcomes

Adverse effects of interventions—Women in the OCS cohort were less likely than women in the RRSO cohort to report that certain potential complications and adverse effects of RRSO influenced their treatment decisions (*i.e.,* anesthesia risks, surgical pain and complications), and were slightly less likely to report that embarrassment from transvaginal ultrasound influenced their decisions. Pain during transvaginal ultrasound was perceived to influence decision equally in both cohorts (Table 2).

Financial costs of interventions—Women in the OCS and RRSO cohorts had similar perceptions regarding the influence of concerns related to surgical insurance coverage on the decision, while women in the OCS cohort were more likely to report that possible lack of screening test-related insurance coverage influenced their treatment decisions (Table 2).

Life disruption from the intervention—More participants in the OCS cohort perceived that life disruption from surgery influenced their decision, while more participants in the RRSO cohort indicated excess time required by periodic screening visits influenced their decision (Table 2).

Sexual and general well-being—Participants in the OCS cohort were more concerned about infertility, loss of femininity, and early menopausal symptoms, while a higher proportion of RRSO participants perceived adverse effects on sex life and anxiety associated with screening visits as influential in their decision. Most women choosing OCS cited the less invasive/radical nature of screening as influential (Table 2).

Perceptions regarding effect of family history on ovarian cancer risk

More participants in the RRSO cohort reported they had reached the age at which female relatives developed cancer (56.1% vs. 50.3%, p=0.008). Seventeen percent of participants believed that cancer in the paternal bloodline meant lower risk to them than inheritance through the maternal bloodline, including 14.6% and 18.1% of RRSO and OCS participants, respectively (p=0.04).

Multivariable analyses: factors influencing choice between RRSO and OCS

Among 2,287 participants completing the medical decision-making questionnaire, 635 participants had missing value for ≥1 of the above factors, and were excluded from the multivariate logistic regression analysis. Among the 1,652 participants analyzed, negative or unknown self-reported mutation status, inability to have children after RRSO, concern about menopausal symptoms, and the perception that screening is less invasive and less radical than surgery were observed to be associated with a higher likelihood of choosing OCS. Among these factors, being negative for a *BRCA* mutation appeared to have the strongest effect on decision-making, with an Odds Ratio (OR) of 0.12 (CI= .07 to .19) favoring OCS. On the other hand, a previous history of any cancer, a family history of OC, reaching the age at which relatives developed cancer, worry related to frequent screening test, concerns about 10 adverse effect of surgery, and concern about the effect of surgery on sexual well-being were associated with a higher likelihood of choosing RRSO. Worry about frequent screening tests and a personal cancer history were most strongly associated with choosing surgery (Table 3).

Analysis of subset of participants who completed a quality of life and cancer risk perception questionnaire at enrollment

By study design, 1,644 participants (620 in the RRSO and 1024 in the OCS cohort) who enrolled prior to April 26, 2006 completed the baseline QOL questionnaire.

Perceived ovarian cancer risk—Fifty-eight percent of participants in the RRSO cohort and 46.3% of participants in the OCS cohort with a valid response estimated their lifetime risk of developing OC to be > 50% (p=0.001). Three percent in the RRSO group and 0.5% in the OCS group estimated their OC risk to be 0%, while 4.9% and 1.8%, respectively, estimated their risk to be 100% (Table 4).

Perceived uncertainty about ovarian cancer risk—Fifty percent of the participants described high subjective ambiguity about their self-reported risk estimate, with 33.7% of participants in the RRSO cohort and 59.3% in the OCS cohort (p=0.001) reporting that they were somewhat or not at all certain about their opinion regarding their estimated chance of getting OC (Table 4).

Ovarian cancer worry—More participants in the RRSO cohort reported worrying about the risk of developing OC very often or almost all the time during the month prior to enrollment compared with participants in the OCS cohort (38.3% *vs.* 15.4%, p<0.001). Twelve percent of participants in the RRSO cohort reported that worrying about OC affected their mood often or all the time compared with 4% in the OCS cohort (p<0.001). Only a small percentage of participants reported that worrying about OC affected their daily activities often or all the time (2.2% of in the RRSO cohort and 0.5% in the OCS cohort, p=0.001).

The Medical Outcome Study Short Form-36 (MOS SF-36)—The Physical and Mental Component scores were slightly, but significantly, higher for those in the OCS cohort (Table 5).

The Functional Assessment of Cancer Therapy–Endocrine Subscale (FACT-ES)—After adjusting for age and menopausal status, menopausal symptoms at enrollment were not significantly different between the OCS and RRSO cohort (difference 0.7, p=0.1, Table 5).

Multivariable analyses: factors influencing choice between RRSO and OCS

Of the participants from whom data on quality of life and cancer worry were collected, 535 were missing ≥1 value and were excluded from the multivariate logistic regression analysis. When SF-36 components scores, FACT-ES scores, cancer risk perception, and cancer worry were included in the multivariate logistic regression analysis, negative or unknown self-reported mutation status, inability to have children after RRSO, concern about menopausal symptoms, and the perception that screening was less invasive/radical than surgery remained significantly associated with selecting OCS as the risk management option. Previous history of any cancer, concerns about adverse effect of surgery, and worry related to frequent screening tests remained significantly associated with choosing surgery. However, a family history of OC and reaching the age at which family members developed cancer were no longer significantly associated with the decision to have RRSO. Instead, uncertainty about their estimated OC risk and the frequency with which the participants worried about OC risk were significantly associated with choosing surgery, with an OR of 2 for both factors (Table 6).

Discussion

In this large, international, multi-institution, prospective cohort study of women at increased genetic risk of OC who chose at study enrollment to undergo either RRSO or OCS, we identified several factors that were associated with choosing one risk management strategy *versus* the other, including selected demographic characteristics, *BRCA1/2* mutation status, perceived OC risk, values regarding outcomes of alternative management options, perceived uncertainty about OC risk, and OC worry.

Similar to previous reports [22], participants in our study who chose RRSO were more likely to be *BRCA* mutation carriers and to have had a personal history of cancer. They were also more likely to perceive that surgical risks and complications, potential effects of RRSO on their sex life, reaching the age at which their female relatives developed cancer, and the anxiety associated with frequent screening tests influenced their choice. Participants in the OCS cohort, on the other hand, were more likely to perceive that infertility, concern about menopausal symptoms, and the degree of invasiveness of the risk management choices influenced their decisions.

The finding that participants choosing RRSO were more concerned about the surgical risk and complications of RRSO is counter-intuitive. We hypothesized that participants choosing OCS would exhibit higher perceived surgical harms. It is possible that the choice of RRSO was driven by other more compelling concerns (*e.g.,* their perceived very high OC risk and OC worry) that over-rode their reservations about surgical risks, or that participants choosing RRSO had received more thorough discussions regarding the procedure.

Ovarian cancer worry and the desire to reduce this worry have both been shown to be associated with intention to undergo RRSO [11, 26, 34]. In our study, women undergoing RRSO were more likely to be mutation carriers, reported higher perceived OC risk, were more certain about their estimated OC risk, and were more frequently worried about developing OC. Consistent with prior observations made in the context of health behavior theories, lower perceived cancer risk and higher perceived uncertainty about cancer risk [35, 36] were associated with choosing the less invasive option. These findings underscore the importance of conveying the most accurate estimate of OC risk to each patient, while directly acknowledging existing inability to precisely estimate individual risk and addressing the individual concerns when discussing management options.

The univariate analysis indicated that various QOL measures differed between the two groups. However, these differences were no longer evident in the multivariate analysis. It is likely that other factors associated with decision-making, such as uncertainty about one's estimated OC risk and OC worry, also influenced one's QOL.

Our data also documented that misperceptions about OC risk as well as the benefits of screening are important, potentially modifiable, factors influencing decisions between RRSO and OCS. The levels of perceived cancer risk in both cohorts were very high. Half of the participants estimated their lifetime OC risk to be >50%, a level exceeding that associated with familial risk or any known hereditary cancer syndrome. Although estimated OC risk was not significantly associated with decision to choose RRSO, inaccurate over-estimates of OC risk, and participants' uncertainties about their own risk estimates, might be reflected in the frequency with which participants worried about developing cancer.

Shared decision-making has been defined as an approach in which clinicians and patients share the best available evidence and personal priorities when faced with "preference-sensitive" decisions in which more than one medically reasonable option exists. The goal of supporting the patients to make informed evidence-based decisions consistent with their personal values could be achieved by a three-step model that includes introducing the choice, describing the options, and helping patients explore their preferences in order to make the decision that best suits their needs [37]. In addition to inaccurate understanding of their own OC risk estimates, genuine ambiguity regarding the long-term non-oncologic sequelae of RRSO in high-risk women compounds the complexity of the decision-making process. Among women at population risk of OC, large observational studies have shown conflicting results in terms of cardiovascular disease and overall mortality associated with bilateral salpingo-oophorectomy among women undergoing hysterectomy for benign indications [38–40]; however, the effects of RRSO on non-oncologic morbidity in high-risk women is unclear and the benefits of OCS remain unproven. While these uncertainties, ambiguities and limitations cannot be fully eliminated at present, their existence warrants thoughtful discussion as patients weigh their management options.

Certain methodological limitations were inherent in the study design. Several of the metrics for syndrome-specific psychosocial factors were designed specifically for this study, and thus have unknown reliability and validity. The questionnaire was completed after the choice between RRSO and OCS had been made (but before surgery); therefore, some responses

might have reflected the effect of the choice, rather than the factors, driving the decision. This may explain the finding that more women choosing RRSO were more concerned about surgical risk and complications, *i.e.,* these concerns may have stemmed from their anticipation of, rather than being the reason for, choosing surgery. Further, respondents were asked to indicate whether an intervention-related concern influenced their decision-making, but were not asked to specify the direction of influence or how important a particular concern was in relation to others, which limits inferences about the relative influence of each concern.

Our study has several strengths. Accrual was designed to emphasize participant recruitment at the community level, rather than through tertiary care genetics referral centers. The single largest accruing institution was a GOG Community Clinical Oncology Program (CCOP) member. The large sample size and the wide range of familial risks (*i.e.,* including both known *BRCA* mutation carriers and strong family history-positive/mutation-negative women) increase the representativeness of our findings for high-risk women for whom OC risk management is clinically indicated. The study was designed to identify factors important to women at the time of decision-making, but before either surgery or screening had been implemented. Participants were surveyed immediately after they made their choice of study intervention, in contrast to prior retrospective studies that collected similar data after the interventions had been implemented, and prospective studies with individuals whose eventual uptake of RRSO may have occurred long after predictive factors were ascertained.

We identified several factors that were important in the decision between RRSO and OCS, including sociodemographic characteristics, *BRCA* mutation status, the perceived risk associated with alternative interventions, and OC worry. We also identified that some of the perceived cancer risks were inaccurate, and that significant misperceptions about OC risk as well as intervention-related risks and benefits existed. Since perceptions of benefits, harms, and uncertainty about OC risk were the major factors influencing decision-making, a thorough discussion emphasizing the current understanding of the risks, benefits, and uncertainties associated with RRSO, and the lack of effective screening, is essential to facilitate a well-informed decision.

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Highlights

- Age and *BRCA1/2* mutation status were associated with risk management option decision
- Ovarian cancer worry was significantly associated with choosing surgery
- Significant misperceptions about personal ovarian cancer risk estimates existed
- Uncertainty about intervention-related risks and benefits were observed

Table 1

Baseline characteristics (N=2,287)

Characteristic	RRSO N*=904 (39.5%) N (%)	OCS N*=1383 ((60.5%) N (%)	P-value
Age Group, total	904	1383	
30–39	176 (19.5)	391 (28.3)	
40–49	378 (41.8)	475 (34.4)	**<0.0001**
50–59	266 (29.4)	374 (27.0)	
60–69	69 (7.6)	122 (8.8)	
≥70	15 (1.7)	21 (1.5)	
Race, total	904	1383	
White	861 (95.2)	1328 (96.0)	0.5
Black	29 (3.2)	31 (2.2)	
Other/Not Specified	14 (1.6)	24 (1.7)	
Menopausal Status, total	904	1383	
Pre-menopausal	525 (58.1)	874 (63.2)	**0.01**
Menopausal	379 (41.9)	509 (36.8)	
Marital Status, total	875	1335	
Married or Living w/Partner	696 (79.5)	1044 (78.2)	
Separated/Divorced	108 (12.3)	151 (11.3)	**0.02**
Widowed	21 (2.4)	21 (1.6)	
Never Married	50 (5.7)	119 (8.9)	
Highest Level of Schooling, total	893	1365	
<HS/HS graduate/GED	117 (13.1)	131 (9.6)	**0.0003**
Some college or tech	223 (25.0)	280 (20.5)	
College graduate or beyond	553 (61.9)	954 (69.9)	
Self-reported Mutation Status, total	904	1383	
Positive	447 (49.4)	223 (16.1)	
Negative	81 (9.0)	296 (21.4)	**<0.0001**
Not tested	298 (33.0)	778 (56.3)	
Tested but no results	70 (7.7)	68 (4.9)	
No response provided	8 (0.9)	18 (1.3)	
Previous history of breast cancer, total	904	1383	
Yes	500 (55.3)	552 (39.9)	**<0.0001**
No	404 (44.7)	831 (60.1)	
Previous history of any cancer, total	904	1383	
Yes	536 (59.3)	610 (44.1)	**<0.0001**

Characteristic	RRSO N*=904 (39.5%) N (%)	OCS N*=1383 ((60.5%) N (%)	P-value
No	368 (40.7)	773 (55.9)	
Female relatives with breast cancer, total	901	1382	
0	148 (16.4)	242 (17.5)	
1	309 (34.2)	445 (32.2)	0.6
2	239 (26.4)	391 (28.3)	
≥3	205 (22.7)	304 (22.0)	
Female relatives with pre-menopausal breast cancer, total	900	1382	
0	404 (44.7)	586 (42.4)	
1	317 (35.1)	553 (40.0)	**0.02**
2	131 (14.5)	197 (14.2)	
≥3	48 (5.3)	46 (3.3)	
Female relatives with ovarian cancer, total	900	1382	
0	447 (49.4)	671 (48.5)	
1	285 (31.5)	450 (32.5)	0.1
2	126 (13.9)	220 (15.9)	
≥3	42 (4.6)	41 (3.0)	

*Cells in which numbers do not add up to total are due to missing values

RRSO: risk-reducing salpingo-oophorectomy, OCS: ovarian cancer screening, HS: high school, GED: Graduate Equivalency Diploma

Table 2

Patient values regarding outcomes related to study interventions

Variable	RRSO (N*=904) N (%)				OCS (N*=1383) N (%)				P-value
	Not at all	Some	Very much	Total	Not at all	Some	Very much	Total	
Perceived Adverse Effects Associated with RRSO or OCS									
Anesthesia was risky	456 (51.1)	358 (40.1)	78 (8.7)	892	786 (60.5)	414 (31.8)	99 (7.6)	1299	**<0.0001**
I might have had lots of pain after surgery	493 (55.4)	339 (38.1)	58 (6.5)	890	848 (65.4)	379 (29.2)	70 (5.4)	1297	**<0.0001**
I might have had complications after surgery	359 (40.4)	464 (52.2)	65 (7.3)	888	633 (48.8)	523 (40.3)	141 (10.9)	1297	**<0.0001**
The vaginal ultrasound examination is embarrassing	753 (86.8)	109 (12.4)	16 (1.8)	888	1197 (88.5)	144 (10.6)	11 (0.8)	1352	**0.04**
The vaginal ultrasound examination is painful	727 (83.4)	127 (14.6)	18 (2.1)	872	1149 (85.2)	179 (13.3)	20 (1.5)	1348	0.3
Financial Costs Associated with each Option									
My insurance wouldn't cover the cost of the surgery	581 (65.5)	228 (25.7)	78 (8.8)	887	841 (65.1)	315 (24.4)	136 (10.5)	1292	0.4
My insurance won't cover the cost of the screening test	639 (73.3)	181 (20.8)	52 (6.0)	872	864 (64.0)	387 (28.7)	99 (7.3)	1350	**<0.0001**
Effect of Intervention on Daily Life									
My life would have been seriously disrupted	524 (58.9)	312 (35.1)	53 (6.0)	889	682 (52.8)	459 (35.6)	150 (11.6)	1291	**<0.0001**
Periodic screening visits take too much time	656 (74.6)	180 (20.5)	43 (4.9)	879	1104 (81.5)	233 (17.2)	17 (1.3)	1354	**<0.0001**
Effect of Each Intervention on Sexual and General Well-Being									
I might feel less feminine after the surgery	608 (68.2)	239 (25.8)	54 (6.0)	901	843 (65.2)	312 (24.1)	138 (10.7)	1293	**0.0009**
My sex life might be harmed as a result of the surgery	485 (54.4)	304 (34.1)	102 (11.4)	891	763 (59.0)	350 (27.1)	180 (13.9)	1293	**0.001**
I would have been upset because I could no longer have more children	808 (90.8)	60 (6.7)	22 (2.5)	890	1046 (80.8)	128 (9.9)	121 (9.3)	1295	**<0.0001**
I might have had significant problems from early menopause	510 (57.6)	276 (31.2)	99 (11.2)	885	626 (48.5)	329 (25.5)	335 (26)	1290	**<0.0001**
I will be worried every time I go in for another exam	372 (42.3)	368 (41.9)	139 (15.8)	879	935 (69.1)	378 (27.9)	40 (3.0)	1353	**<0.0001**
Screening is less invasive, less radical than surgery	468 (58.9)	247 (31.1)	80 (10.1)	795	131 (9.8)	316 (23.7)	886 (66.5)	1332	**<0.0001**

* The differences in total numbers are due to missing values

RRSO: risk-reducing salpingo-oophorectomy, OCS: ovarian cancer screening

Table 3

Multivariable analysis of factors associated with the choice between RRSO and OCS (N=1,652)

Variables	Odds Ratio*	95% CI		P-value
Self-Reported Mutation Status				
Not Tested vs Positive	0.181	0.125	0.262	**<.0001**
Tested but Results Unknown vs Positive	0.425	0.221	0.818	
Negative vs Positive	0.115	0.070	0.190	
Previous Cancer History (Any)	2.135	1.519	3.001	**<.0001**
Female relatives with ovarian cancer	1.320	1.102	1.582	**0.0026**
Anesthesia was risky	1.733	1.347	2.230	**<.0001**
I might have had lots of pain after surgery	1.670	1.280	2.178	**0.0002**
My sex life might be harmed as a result of the surgery	1.360	1.056	1.751	**0.0173**
I would have been upset because I could no longer have more children	0.480	0.349	0.659	**<.0001**
I might have had significant problems from early menopause	0.572	0.451	0.727	**<.0001**
I will be worried every time I go in for another exam	2.661	2.058	3.440	**<.0001**
Screening is less invasive, less radical than surgery	0.128	0.103	0.160	**<.0001**
I have reached the same age at which other women in my family have developed cancer	1.459	1.080	1.972	**0.0139**

*An OR>1 indicates that the variable is associated with choosing RRSO over OCS, while an OR<1 indicates that the variable is associated with choosing OCS over RRSO

Table 4

Perceived lifetime risk of ovarian cancer

Variable	RRSO (N=1024) N (%)	OCS (N=620) N (%)	P-value
Risk of developing ovarian cancer			
100%	30 (4.9)	18 (1.8)	
75%–99%	133 (21.8)	141 (14.0)	
50%–74%	193 (31.7)	306 (30.5)	**<0.001**
25%–49%	138 (22.7)	269 (26.8)	
10%–24%	54 (8.9)	183 (18.2)	
1%–9%	42 (6.9)	81 (8.1)	
0%	19 (3.1)	5 (0.5)	
Certainty about the chances of getting ovarian cancer			
Somewhat or not at all certain	203 (33.7)	594 (59.3)	**0.001**
Fairly or very certain	400 (66.3)	408 (40.7)	

Table 5

Quality of Life Measurements

Instruments	OCS (N=1024)		RRSO (N=620)		Difference	P-value
	N*	Mean ± SD	N*	Mean ± SD	(95% CI)	
SF-36	968		587			
PCS_c		50.4 ± 9.6		49.5 ± 10.5	0.9 (−0.15~1.9)	0.0204
MCS_c		51.0 ± 9.0		48.8 ± 11.1	2.1 (1.1~3.2)	<0.0001
FACT-ES	1013	60.7 ± 8.2	616	60.0 ± 8.4	0.76 (−0.08~1.6)	0.073

*Participants with missing values were excluded.

Table 6

Multivariable analysis of factors associated with the choice between RRSO and OCS, including quality of life and cancer worry data (N=1109)

Variables	Odds Ratio*	95% CI		P-value
Self-Reported Mutation Status:				
Not Tested vs Positive	0.268	0.170	0.421	**<.0001**
Tested but Results Unknown vs Positive	0.638	0.301	1.354	
Negative vs Positive	0.181	0.096	0.343	
Previous Cancer History (Any)	1.723	1.166	2.547	**0.0063**
Anesthesia was risky	1.981	1.444	2.716	**<.0001**
I might have had lots of pain after surgery	1.612	1.169	2.223	**0.0036**
I would have been upset because I could no longer have more children	0.564	0.387	0.823	**0.0030**
I might have had significant problems from early menopause	0.594	0.451	0.782	**0.0002**
I will be worried every time I go in for another exam	2.203	1.590	3.052	**<.0001**
Screening is less invasive, less radical than surgery	0.139	0.107	0.182	**<.0001**
Risk of ovarian cancer certainty	1.977	1.352	2.890	**0.0004**
Risk of ovarian cancer frequency of worry	1.977	1.282	3.049	**0.0021**

*An OR>1 indicates that the variable is associated with choosing RRSO over OCS, while an OR<1 indicates that the variable is associated with choosing OCS over RRSO