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Risk Perception, Worry, and Test Acceptance in Average-Risk Women Undergoing Ovarian Cancer Screening

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Abstract

OBJECTIVE—We evaluated baseline knowledge of ovarian cancer risk and perceptions toward ovarian cancer screening (OCS) in women initiating the normal risk ovarian screening study (NROSS).

STUDY DESIGN—Average-risk, postmenopausal women were enrolled between 2001 and 2011 as they entered the NROSS. Participants completed baseline surveys of risk perception, cancer worry (Cancer Worry Scale), anxiety (State-Trait Anxiety Inventory), health and well-being (SF-36), and acceptability of OCS.

RESULTS—Of the 1242 women enrolled, 925 (74.5%) completed surveys. The respondents estimated a mean lifetime risk of ovarian cancer of 29.9%, much higher than the actual risk of 1.4% for women in the U.S. Only 2.8% of participants correctly estimated their risk, while 35.4% reported their lifetime risk to be 50%. Cancer worry was low, with a median CWS score of 7 out of 24. Anxiety was comparable to published norms for women in this age group, with median STAI-S and STAI-T scores of 30 and 29 out of 80, respectively. Overall, women reported good physical and mental well-being. In terms of OCS acceptability, 97.2% of respondents agreed, or strongly agreed, that “the benefits of screening outweigh the difficulties.” Very few women were reluctant to undergo OCS due to time constraints (1.1%), pain (2.0%), or embarrassment (1.9%).

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CONCLUSIONS—Average-risk women undergoing OCS highly overestimated their risk of ovarian cancer. Despite this, participants reported low cancer worry and anxiety. The discrepancy between knowledge of and attitudes toward ovarian cancer risk highlights the need for educational efforts in this area.

Key Phrases

Cancer Worry; Ovarian Cancer Screening; Risk Perception; Test Acceptability

Introduction

Though not common, ovarian cancer is the most deadly gynecologic malignancy, with 22,000 new cases and more than 14,000 deaths anticipated in 2013.¹ While stage I disease is associated with a 90% five-year survival rate, the prognosis for advanced stages is poor. Secondary to the nonspecific symptoms of early ovarian cancer, 80% of women are stage III or IV at time of diagnosis.² One strategy to decrease the mortality rate is to establish an effective method for detection of early-stage ovarian cancer. To date, however, potential screening methods for ovarian cancer have had unacceptably high false positive rates without any demonstration of a significant reduction in ovarian cancer mortality, leading to recommendations against routine ovarian cancer screening for the general population.³

A single-arm, multi-institutional, prospective study of ovarian cancer screening utilizing the Risk of Ovarian Cancer Algorithm (ROCA), known as the Normal Risk Ovarian Screening Study (NROSS), is currently underway in the United States. This study involves annual CA125 measurements in postmenopausal women who have an average (e.g. normal, population-based) risk of developing ovarian cancer. The screening algorithm incorporates a woman's age and the change in her CA-125 over time to estimate her risk of having undetected ovarian cancer. Women deemed to be at intermediate risk (between 1 in 2000 to 1 in 500) are triaged to undergo a repeat CA125 measurement in three months, while women found to be at elevated risk are triaged to undergo a transvaginal ultrasound and referral to a gynecologic oncologist. Recently published results demonstrate that ovarian cancer screening with the ROCA is feasible with a positive predictive value of 40% and a specificity of 99.9%.⁴

There have been few published studies regarding ovarian cancer knowledge and risk perception among average-risk women undergoing ovarian cancer screening. Baseline analysis of participants in the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS), a prospective trial of ovarian cancer screening in the U.K., found that while over 40% of women correctly identified their risk, approximately half of respondents underestimated their ovarian cancer risk.⁵ In contrast, studies in the U.S. have found that most American women tend to overestimate their ovarian cancer risk.⁶ This lack of knowledge regarding personal cancer risk is not surprising given that multiple studies have demonstrated that women are generally unaware of ovarian cancer risk factors.^{5,7,8} Little is known about ovarian cancer worry or acceptance of screening among average-risk women undergoing ovarian cancer screening.

The present study was designed as a companion to the NROSS. We aimed to prospectively assess ovarian cancer risk perception, ovarian cancer worry, and acceptability of ovarian cancer screening among women initiating an ovarian cancer screening trial that utilizes the ROCA.

Materials and Methods

Between July 2001 and October 2012, 1,457 women were prospectively enrolled in the NROSS at MD Anderson Cancer Center. The majority of these women were recruited to the trial from MD Anderson's Cancer Prevention Clinic, a clinic that provides care to patients without active cancer. Other participants found out about the trial through word-of-mouth from women already enrolled in the trial. Women eligible for the NROSS were postmenopausal, between 50 to 75 years old, had at least one ovary, had no active cancer and no history of ovarian cancer, and were willing to undergo annual blood draws, follow-up CA125 measurements, and transvaginal ultrasound as recommended by the NROSS protocol. Women were ineligible if they were at high risk for developing ovarian cancer. High-risk was defined as a patient with at least one of the following: 1) *BRCA1* or *BRCA2* mutation, 2) known or suspected Lynch syndrome, 3) a first or second degree male relative with breast cancer, 4) Ashkenazi Jewish descent with premenopausal breast cancer or a family history of ovarian cancer or premenopausal breast cancer, or 5) two first or second degree relatives with ovarian cancer, premenopausal breast cancer, or both. The full details of the NROSS protocol have been previously published.⁴

After informed consent was obtained for NROSS, women who could read and speak English were offered participation in the questionnaire portion of the trial. Due to financial constraints, only NROSS participants at MD Anderson Cancer Center were asked to enroll in the questionnaire study. Of the 1,457 women eligible for the survey, 1,242 (85.2%) provided separate written, informed consent to participate prior to study enrollment. This study was approved by the Institutional Review Board of The University of Texas MD Anderson Cancer Center.

Upon entry into the study and prior to undergoing ovarian cancer screening, participants were given the study questionnaires. Patient demographics and medical history were collected prospectively. The survey assessed ovarian cancer risk perception and acceptability of ovarian cancer screening, ovarian cancer worry via a modified Lerman breast cancer worry scale, anxiety using the Spielberger State/Trait Anxiety Inventory (STAI), and general quality of life with the SF-36.^{9–11} No educational materials were provided as part of this study.

The SF-36, STAI, and the Cancer Worry Scale were scored according to the respective scoring mechanism for each instrument. Baseline demographic information was summarized using descriptive statistics, including medians, means, standard deviations, ranges, and frequencies. Mann-Whitney U and chi-square tests were used to compare differences between groups. IBM SPSS Statistics for Windows, Version 19.0, was used for statistical analysis (IBM Corp., Armonk, NY). A two-sided p value of less than 0.05 was considered statistically significant.

Results

Of the 1,242 women enrolled in the study, 925 (74.5%) completed surveys. Table 1 compares the demographics of women that completed surveys (responders) to those who did not (non-responders). Overall, the groups were similar, though responders were slightly older and more likely to be white than non-responders.

In general, survey participants highly overestimated their risk of ovarian cancer. Respondents estimated their mean lifetime risk to be 29.9%. Approximately one-fifth of the participants stated that their risk of ovarian cancer was between 25–49%, and more than one-third believed their risk to be 50%. Only 2.8% of women correctly identified their risk as 1–2% (Table 2). When asked what their chances of getting ovarian cancer were compared to “other women your age,” 45.3% of the respondents said they were “about the same.” However, 22.2% believed their ovarian cancer risk was “a little higher” or “much higher” than other women. Interestingly, only 26.4% of the women that responded noted that they were “fairly certain” or “very certain” about their opinions on ovarian cancer risk. Of note, 55% of respondents said they received their information about ovarian cancer from television, newspapers, or magazines, while just over one-quarter relied on their healthcare provider for this information.

Although survey participants tended to overestimate their risk of ovarian cancer, they were optimistic regarding the ability to screen for the disease. Of the respondents, 93.6% “agreed” or “strongly agreed” that ovarian cancer could be cured when detected early. Furthermore, 91.5% believed that transvaginal ultrasonography could detect ovarian cancer at a stage when it could be cured, while 86.4% thought the same of a single CA125 value. Additionally, in spite of perceiving themselves to be at high risk for ovarian cancer, few women (12%) were afraid that their ovarian cancer screening results would be abnormal. Likewise, only 4.4% of respondents reported that they often thought about ovarian cancer, while 0.6% stated that thoughts about ovarian cancer affected their mood and 0.3% reported that thoughts about ovarian cancer interfered with their ability to perform their daily activities.

A modified cancer worry scale and the STAI were utilized to objectively measure study participants’ anxiety and ovarian cancer worry. As expected given participants’ responses regarding frequency of ovarian cancer thoughts, cancer worry was low with a median score of 7.0 (range 6.0 to 20.0) out of 24. The STAI also found anxiety to be low overall. The median STAI-State (STAI-S) score, which measures anxiety about an event, was 30 out of 80. The median STAI-Trait (STAI-T) score, which measures one’s baseline anxiety, was 29 out of 80. This is comparable to the published norms of postmenopausal women for these scales of 32.2 and 31.79, respectively.¹¹

As evidenced by the SF-36 scores, study participants demonstrated good physical and mental health. Table 3 lists participants’ median scores for each of the eight scales on the SF-36 as well as the 50th and 75th percentiles of SF-36 scores for women in the general population in the United States.¹⁰

Survey participants were also queried regarding acceptability of ovarian cancer screening (Table 4). The overwhelming majority of women “agreed” or “strongly agreed” that there were more benefits to ovarian cancer screening than difficulties. Very few women said pain, embarrassment, or time constraints were reasons they would be reluctant to undergo screening. The most commonly cited reason to not be screened was fear of insurance not covering the cost of the tests.

Post-hoc subgroup analyses were performed on women with a history of breast cancer and women with no personal cancer history. Women with a breast cancer history had significantly higher median estimates of their lifetime ovarian cancer risk than women with no cancer history (35.0% versus 25.0%, $p=0.001$). Additionally, breast cancer survivors tended to have poorer physical functioning than women with no cancer history, with significantly worse scores on all four physical functioning scales of the SF-36 (all $p<0.05$). However, there were no statistically significant differences between groups in other aspects of the survey, including the cancer worry scale, the STAI-S, the STAI-T, or acceptability of ovarian cancer screening (all $p>0.05$).

Comment

As anticipated, our study population demonstrated minimal baseline knowledge of ovarian cancer risk. Though most study participants reported that they believed their risk of developing ovarian cancer was similar to other women their age, few correctly identified their ovarian cancer risk. In fact, the majority of women greatly overestimated their risk. This result is in contrast to those of the baseline survey of UKCTOCS participants. When queried about their personal ovarian cancer risk, 42.3% of women in the UKCTOCS study accurately identified their risk as 1 in 70, while 50.1% underestimated their risk at 1 in 500.⁵ The discrepancy between the findings of the UKCTOCS study and those in our study may be a reflection of the difference between populations in the U.K. and U.S., as other studies performed in the U.S. have found that both average- and high-risk women tend to overestimate their ovarian cancer risk.^{6, 12}

Additionally, while women in the present study were asked to provide their ovarian cancer risk on a scale of 0–100 percent, women in UKCTOCS were asked in a multiple choice fashion with possible answers ranging from 1 in 12 to 1 in 500. It is well established that people interpret information differently based upon the manner in which it is presented or “framed.” This is known as the “framing effect” and may account for the differences in results seen in the two studies.¹³

Despite survey participants’ perception that their ovarian cancer risk was very high, the median scores for the Cancer Worry Scale, STAI-T, and STAI-S suggest that overall worry and anxiety associated with ovarian cancer were low. The reasons for this discrepancy are unclear. Studies of high-risk women undergoing ovarian cancer screening have demonstrated an association between high levels of perceived ovarian cancer risk and high levels of anxiety.^{14,15} To date, however, there have been no published studies that have assessed cancer-related anxiety or worry among women with average-risk undergoing cancer screening. Additionally, despite the current lack of evidence in support of population-

based screening, the majority of respondents indicated that early-stage ovarian cancer can be cured, and that transvaginal ultrasound or a single CA125 would be sufficient to detect ovarian cancer at an early stage. This belief about ovarian cancer screening may explain the incongruity between participants' perceptions of ovarian cancer risk and their reported worry and anxiety.

Ovarian cancer screening was acceptable to our study population. A small number of women were concerned that the blood tests and ultrasounds would be too painful, time consuming, or embarrassing. The most commonly cited reason against screening was fear that insurance would not cover the procedures. However, only 21% of respondents believed that this would be an issue. Furthermore, the vast majority of respondents believed that the benefits of screening outweighed any difficulties. It should be noted that few survey questions addressed ovarian cancer screening acceptability, and that these questions were phrased in the form of statements with which respondents were asked to agree or disagree. This may limit the conclusions that can be made regarding ovarian cancer screening acceptability among our population. However, our results mirror the findings from the small number of other studies that have attempted to determine women's acceptability of ovarian cancer screening. In their study of more than 2,200 average-risk women undergoing "symptom triggered" ovarian cancer screening, Goff and colleagues reported that most women found the screening for symptoms to be acceptable. Furthermore, the women who underwent CA125 or transvaginal ultrasound had a high rate of acceptability for the procedures. However, only 27 of the 47 women who underwent a procedure completed a survey.¹⁶

Our study participants' misperceptions regarding personal risk of ovarian cancer emphasize the need for education in this area. Prior studies have also demonstrated a lack of awareness regarding gynecologic malignancies among American women. With respect to ovarian cancer specifically, study populations have repeatedly displayed little knowledge regarding risk factors and symptoms.^{8,17} To complicate matters, it appears that many women learn about ovarian cancer from the mass media. In our own study, more than 50% of respondents reported receiving their ovarian cancer information from the media, while only 25% spoke to their health care provider about it. However, where women learn about ovarian cancer may be due to more than simply patient preference. In one survey of over 1,200 women, 80% of respondents reported that their physician had never discussed symptoms and risk factors of ovarian cancer with them.⁸ Educational initiatives, such as the CDC's *Inside Knowledge: Get the Facts about Gynecologic Cancer*, have been developed in an attempt to use the media to raise gynecologic cancer awareness.¹⁸ However, the impact of these campaigns is not yet known.

Educational efforts also need to be focused on screening for ovarian cancer. There is evidence that women in the general population erroneously believe that routine tests, such as the Papanicolaou test, screen for a variety of malignancies, including ovarian cancer.^{8,17} Furthermore, despite the lack of conclusive evidence to support widespread ovarian cancer screening, the present study and the survey of UKCTOCS participants found that women tend to believe that ovarian cancer screening will lead to fewer advanced-stage cancers and improve morbidity.⁵ Though the preliminary findings of the UKCTOCS and NROSS are

promising, the final results are not yet available.^{4,19} If they support the implementation of ovarian cancer screening for the general population, it is critical that women are educated regarding the benefits and possible limitations of ovarian cancer screening.

A potential for bias in our study lies in the method by which our study population was recruited. All study participants volunteered to enroll in a study of ovarian cancer screening, and the majority of them were recruited from a cancer prevention clinic at MD Anderson. As such, their attitudes and beliefs regarding ovarian cancer screening are potentially different from those of women in the general population. Additionally, the majority of the women in the study were white, meaning our results may not be generalizable to a minority population. Another limitation is the potential for non-response bias. This bias is likely minimal, however, given our high overall response rate and the few differences noted between survey responders and non-responders (Table 1). It should also be noted that some women did not answer all survey questions. Potential reasons for this include that they did not feel that they had time to complete the survey, they did not know some of the answers to some questions, or that they were not comfortable with some of the questions.

In our study, all participants answered survey questions prior to undergoing ovarian cancer screening. While it is valuable to understand how women feel about ovarian cancer screening at baseline as this indicates how likely they are to initiate screening, it is possible that their opinions may change once they have had experience with screening. Additionally, a subset of women undergoing screening will have false-positive results that prompt additional testing. It is important to evaluate whether these women have a change in their anxiety, cancer worry, or psychological well-being as compared with women that only have normal testing. We are currently attempting to assess this in our study population by administering follow-up surveys to those women that have undergone ovarian cancer screening for at least one year.

In conclusion, the results from this study suggest that ovarian cancer screening is acceptable to postmenopausal women at average-risk for ovarian cancer. Furthermore, anxiety and cancer worry were low among the study population as a whole. These findings are encouraging as we await the results of the UKCTOCS and NROSS trials. However, while many women reportedly receive information regarding ovarian cancer from the media, the majority of study participants demonstrated a significant lack of understanding regarding their ovarian cancer risk and the current utility of ovarian cancer screening. This suggests that using mass media as a mechanism to promote ovarian cancer knowledge and awareness may be an effective way to educate patients.

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Figure 1.
Respondents Estimate of Personal Ovarian Cancer Risk

Table 1

Demographics of Survey Responders versus Non-Responders (N=1,242)

Variable	Responders (n=925)	Non-Responders (n=317)	p
Age	Years	Years	0.004
Median (Range)	59 (50–74)	58 (50–74)	
Mean	60.1	59	
Race	% (n)	% (n)	<0.001
White	85.6 (792)	74.4 (236)	
African-American	4.6 (43)	9.1 (29)	
Hispanic	4.6 (43)	9.5 (30)	
Asian	5.0 (46)	6.6 (21)	
Other	0.1 (1)	0.3 (1)	
Parity	% (n)	% (n)	0.325
Parous	80.5 (745)	81.1 (257)	
Nulliparous	19.4 (179)	16.4 (52)	
Unknown	0.1 (1)	2.5 (8)	
Cancer History	% (n)	% (n)	0.101
No History	43.5 (402)	45.8 (145)	
Breast Cancer History	25.3 (234)	25.2 (80)	
Other Cancer History	31.2 (289)	29.0 (92)	
Family History	% (n)	% (n)	0.185
Breast Cancer	35.1 (325)	31.2 (99)	
Family History	% (n)	% (n)	0.782
Ovarian Cancer	7.7 (71)	8.2 (26)	

Table 2

Median SF-36 Scores of Survey Respondents Compared with Norms for Women in the U.S.

SF-36 Scale	Median Survey Participant Score	50 th Percentile for Women in the U.S. ¹⁰	75 th Percentile for Women in the U.S. ¹⁰
Physical Functioning	90.0	90.0	100.0
Role-Physical	100.0	100.0	100.0
Bodily Pain	84.0	74.0	100.0
General Health	82.0	72.0	85.0
Vitality	70.0	60.0	75.0
Social Functioning	100.0	87.5	100.0
Role-Emotional	100.0	100.0	100.0
Mental Health	88.0	80.0	88.0

Table 3

Ovarian Cancer Screening Acceptability Survey Questions

Survey Questions*	% Agree/Strongly Agree (n = Respondants)
The benefits of ovarian cancer screening outweigh the difficulties.	97.2 (818)
I don't have time for ovarian cancer screening.	1.1 (826)
I am reluctant to undergo ovarian cancer screening because the procedures are painful.	2.0 (814)
I am reluctant to undergo ovarian cancer screening because the procedures are embarrassing.	1.9 (820)
I am reluctant to undergo ovarian cancer screening because my insurance won't pay for the tests.	21.8 (792)

* Participants were asked if they strongly agree, agree, disagree, or strongly disagree with these statements.