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## Understanding the Needs of Women Considering Risk Reducing Salpingo-Oophorectomy

**Ms. Carol Cherry, MSN, RN, AOCNS, Dr. Mary Ropka, PhD, RN, Ms. Jennifer Lyle, MA, Dr. Laura Napolitano, PhD, and Dr. Mary B. Daly, MD, PhD**

Women's Cancer Center, Fox Chase Cancer Center, Philadelphia, Pennsylvania (Ms Cherry); University of Virginia School of Medicine, Charlottesville, Virginia (Dr Ropka); National Comprehensive Cancer Network, Fort Washington, Pennsylvania (Ms Lyle); Chapin Hall at the University of Chicago, Chicago, Illinois (Dr Napolitano); Department of Clinical Genetics, Fox Chase Cancer Center, Philadelphia, Pennsylvania (Dr Daly)

### Abstract

**Background**—Because of the significantly increased lifetime risk of ovarian cancer associated with inheritance of a germline mutation in the *BRCA1/2* genes, women with a deleterious mutation are recommended to undergo risk-reducing salpingo-oophorectomy (RRSO) at age 35 or once child-bearing is complete. Significant time is often spent by nurses trained in genetics providing counseling to improve the decision-making process. The decision to undergo surgery is complex and laden with several sources of uncertainty.

**Objective**—We conducted a qualitative study among female carriers of deleterious *BRCA1/2* mutations to address these uncertainties.

**Interventions/Method**—Twelve qualitative interviews were conducted with women who had received a positive *BRCA1/2* test result to explore their understanding of ovarian cancer risk, prevention options and resource needs. Qualitative content analysis was performed.

**Results**—Significant information gaps in level of risk, other factors associated with ovarian cancer, and details of prophylactic oophorectomy were identified. Personal experience with cancer colored the degree of risk perception associated with the inherited mutation. Fear of the side effects of surgical menopause, both physiologic and psychosocial, was common. Women expressed interest in hearing from other women facing the same decision.

**Conclusions**—Women facing the decision to undergo RRSO have several information gaps and unmet needs despite comprehensive counseling.

**Implications for Practice**—Based on our findings, we make specific recommendations that will guide nursing practice and future research.

### Keywords

BRCA1/2 positive women; ovarian cancer risk; risk reducing Salpingo-oophorectomy; decision making; risk perception; uncertainty

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Correspondence: Mary B. Daly, MD, PhD, Department of Clinical Genetics, Fox Chase Cancer Center, 333 Cottman Avenue, Philadelphia, PA 19111 (mary.daly@fccc.edu).

Conflicts of Interest

The authors have no conflicts of interest to disclose.

## Introduction

Inheritance of a mutation in the *BRCA1/2* genes confers a risk for ovarian cancer that is much higher than in the general population. Estimates of lifetime ovarian cancer risk range from 36–46% for *BRCA1* carriers and from 10–27% for *BRCA2* carriers<sup>1,2</sup> and remains elevated across all age groups<sup>3</sup>. Because of this significantly elevated risk, and lack of effective screening for ovarian cancer<sup>4</sup>, women with *BRCA1/2* mutations are recommended to undergo risk-reducing salpingo-oophorectomy (RRSO) at age 35 or once child-bearing is complete<sup>5</sup>. A recent meta-analysis suggests a 79% reduction in ovarian/fallopian tube cancer risk and a 53% reduction in breast cancer risk after oophorectomy in these women<sup>6</sup>. A prospective multicenter study of 2482 women with *BRCA1/2* mutations reported that these risk reductions translated into lower breast and ovarian cancer mortality<sup>7</sup>. RRSO has also been shown to reduce cancer-related anxiety and worry<sup>8,9</sup>.

While it is widely recognized that RRSO offers the best protection from ovarian cancer for women with *BRCA1/2* mutations, the decision to undergo surgery is complex and laden with uncertainty<sup>10</sup>. First is the fundamental uncertainty about the magnitude and nature of the ovarian cancer risk<sup>11</sup>. In addition to the broad range of ovarian cancer risk estimates, risk may differ by specific gene (*BRCA1* vs. *BRCA2*) and by mutation-specific site<sup>12</sup>. Age at diagnosis of ovarian cancer in mutation carriers is variable, raising uncertainty about optimal timing of surgery. Although RRSO reduces risk of ovarian cancer, a residual risk of primary peritoneal cancer persists<sup>13</sup>, resulting in uncertainty about the overall benefits.

Nurses trained in genetics often spend significant time helping women as they weigh their options for surgery. Women considering RRSO must consider its adverse health and psychologic consequences<sup>14</sup>. Premenopausal women choosing RRSO must accept the short-term surgical risk and the long-term physiologic and psychologic consequences of surgical menopause, including the immediate onset of vasomotor symptoms and lifetime risk for osteoporosis and cardiovascular disease. The complexities and uncertainties surrounding this decision are reflected in considerable variation in the uptake of RRSO and its timing, with many women waiting to reach an age closer to menopause before proceeding<sup>15,16</sup>. Interventions which provide accurate risk estimates, clear risk management options, and the support women need to explore and adopt personalized risk reduction measures are needed<sup>17</sup>.

To guide development of a personalized approach to decision making, we conducted a qualitative study among women with deleterious *BRCA1/2* mutations to explore: 1) perceptions of their ovarian cancer risk; 2) understanding of their ovarian cancer risk-reduction options; 3) decision-making needs related to their risk reduction options. The research team represents expertise in hereditary cancer syndromes, clinical nursing, public health, decision support and qualitative methods. This data will inform the development of a decision support tool for evaluation in the clinical setting.

## Methods

### Sample

The sample was purposefully chosen to represent a range of variability in age (22–29, 30–49, 50+ years) and breast cancer history (affected, unaffected). Eligible women 1) were age 21 years or older, 2) had thorough pre- and post-disclosure genetic counseling, 3) had a true positive *BRCA1/2* genetic test result within the past 24 months, 4) had not had ovarian cancer, 5) had at least one intact ovary, and 6) gave informed consent. Participants were recruited in person from the high-risk clinics at Fox Chase Cancer Center (FCCC), which has been offering genetic risk assessment and genetic testing for over 15 years. After a

thorough description of the study, interested women completed a consent form and arranged an appointment to be contacted by phone for the interview. Phone interviews were chosen to minimize participant burden.

### Data Collection

All phone interviews were conducted by a Master's prepared nurse interviewer trained in qualitative study design and familiar with ovarian cancer risk counseling. She followed a guide which included a standardized set of open-ended questions to assure that the same information was sought from each participant and minimize interviewer variation. The script sought information on eight content areas (Table 1) which were derived from our experience in counseling over 500 women who have received *BRCA1/2* test results. Interviews lasted approximately one hour. All interviews were audio-recorded and transcribed, with accuracy checked in full. The study was approved by the FCCC Institutional Review Board.

### Data Analysis

Because little empirical work has addressed this question, we chose a qualitative design<sup>18</sup> to generate an in-depth understanding of the experiences of *BRCA1/2* positive women. We chose a grounded inductive method for the data analysis to provide insight into the complex processes involved in risk perception and how risk is managed within individual, familial and societal contexts, while not imposing a predetermined framework on the interviews. This allows us to organize complex processes into broad categories that can inform health communication strategies<sup>19,20</sup>. However, the content of the interview questions was consistent with a perspective in which knowledge and competence are both related to decision making. In the first stage of coding, two co-authors read through the transcripts to identify key issues and concepts, leading to the development of a thematic framework. Utilizing this framework, the team developed codes and coded all twelve interviews jointly to minimize interpretive discrepancies. Frequency of specific responses within these categories was calculated, analyzed and reviewed to generate summary descriptions of the patterns obtained. Coded responses were examined for themes regarding breast and ovarian cancer risk and risk reduction options and uncertainty surrounding both.

### Results

Twelve women who had received positive *BRCA1/2* genetic tests (9 *BRCA1* and 3 *BRCA2*) within the past twenty-four months were interviewed. Three women had been diagnosed with breast cancer and 9 were unaffected. Ages ranged from 23 to 57, with a mean age of 39.5 years. All women were Caucasian. The majority (7) of the women had attained a bachelor's degree, 2 had advanced degrees, and 3 had completed high school. Seven of the women were premenopausal, and five were peri- or postmenopausal.

We identified three major themes in the interviews. Each had discrete subcategories

#### Perception of Ovarian Cancer Risk

**Risk Associated with Genetic Test Result**—Knowledge about ovarian cancer risk varied considerably as reported by these women, all of whom had received genetic counseling. When asked specifically about their risk for ovarian cancer, the majority of women used qualitative terms such as, “*somewhat higher...*,” “*very high...*,” “*a good chance of me getting ovarian cancer...*” Among the four women who quoted a lifetime percentage, their estimates ranged from 10% to 90% lifetime risk.

**Risk associated with personal and family history**—Each woman's family history strongly influenced how she interpreted her *BRCA1/2* test result in terms of her personal

risk. Both the personal experience of cancer and that of witnessing a family member deal with cancer formed a filter through which the positive genetic test result was viewed.

“...what it meant is that I was at higher risk for breast cancer because that, that’s been our kind of family legacy.”

Women who have not experienced ovarian cancer in their family tended to minimize their risk for ovarian cancer and to question whether the drastic step of prophylactic surgery was necessary in their case.

“I have a little bit higher risk than everyone else because of carrying the BRCA2 gene...the thing that makes me less fearful of it is because there is no family history of it.”

The profound impact of their personal experience also tended to create a barrier between the women receiving test results and the rest of the world, including clinicians who may not have had similar experiences and whose advice may therefore have been questioned.

**Information gaps**—In addition to uncertainties about the risk conferred by a deleterious mutation, there were gaps in knowledge about other risk factors related to ovarian cancer. The majority of women could not identify any ovarian cancer-specific risk factors. Diet, alcohol, exercise, the environment and “*luck of the draw*” were mentioned by a few, but more as global risk factors for cancer and not specific to ovarian cancer. Some women felt overwhelmed by the amount of information available and had difficulty applying it to their situation.

“I know that when I learned about the results of the genetic test I was very emotional so I really don’t think I absorbed the information.”

They also reported lack of resources and information about the effects of surgical menopause, especially for younger women.

“...I think we just don’t know a lot, there is not a lot of literature that says when women have their ovaries removed between the age of 25 and 35 here is how they turn out...”

**Areas of fear and uncertainty**—Many women expressed generalized fear and/or uncertainty about ovarian cancer risk and their ability to cope with risk over time. In many cases the fear was triggered and intensified around the time of undergoing screening tests. A common reason for not following screening recommendations was the desire not to have to think about it.

“... the fear that comes every 6 months of going for an exam and of course then have to keep going for ultrasounds and biopsies and the like.”

Fear also resulted in avoidance or denial of the topic by a minority of women and their family members, who felt that talking about it made it feel more real.

“While I am very aware that my breast cancer is at a younger age than most women, ...I don’t need to deal with this today.”

## Understanding of Ovarian Cancer Risk-Reduction Options

**Type of prophylactic surgery**—All of the women were aware of the option of RRSO. The majority were unsure of the degree of risk reduction associated with RRSO, and one woman was skeptical about the validity of the data to support surgery as a way to reduce risk. Four of the women were unaware of the effect of RRSO on reducing breast cancer risk, two of whom believed that removing the ovaries increased the risk of breast cancer.

“I believe it increases your chance of breast cancer, because we don’t have that hormone estrogen.”

Other than three women who were in the health care field and two who had a mother or sister who had already had prophylactic oophorectomy, the majority of women had very little information about details of the surgery, the choice between laparoscopic or full abdominal surgery, the importance and indications for removing the fallopian tubes and/or the uterus, and side effects of these various procedures.

**Timing of prophylactic surgery**—While almost all of the women had accepted the benefits of undergoing RRSO, the majority had questions about its timing. Childbearing was an important issue for younger women who had not had children.

“Having a family and being a mother is very important to me and so my decision would be made more difficult if I don’t have a family by the time I need to make that ultimate decision.”

Only one young woman, aged 28, whose mother died at 30 from breast cancer, was willing to forgo having children to proceed with RRSO. For premenopausal women, the most consistent factor affecting timing of the surgery was the desire to forestall premature menopause. Many of the women cited a long litany of anticipated menopausal symptoms, including hot flashes, night sweats, mood swings, vaginal dryness, loss of libido and weight gain.

“You know, the dryness, the lack of sex drive, and all of that, I just am not ready for that.”

Some were concerned about the impact of RRSO on their sense of themselves as a woman and their relationship with their husband.

“...I am getting older, maybe I am not as attractive to my husband, maybe adding this one more thing is something that I don’t want to choose.”

Other common concerns were depression, bone loss, aches and pains and cardiovascular disease. All but two of the women were aware of the option of hormone replacement therapy (HRT) to alleviate some of these, but over half were concerned about the potential of HRT to increase their risk of breast cancer.

**Other factors**—Some of the fear and uncertainty surrounding risk-reducing options is related to the general awareness of the lack of effective screening. Even among the five women who were undergoing regular screening with transvaginal ultrasound and CA 125, the majority acknowledged that the tests were “...*not foolproof*.”

There was lack of knowledge about oral contraceptive pills (OCPs) as an option for reducing risk for ovarian cancer, their impact on breast cancer risk, and a general reluctance to use “*man made*” hormones. Ten of the twelve women knew very little to nothing about OCPs to reduce risk, and only one woman reported currently taking them for chemoprevention. All of the responses regarding healthy lifestyle behaviors to reduce ovarian cancer risk were framed as lifestyle behaviors to promote health in general, not specific to lowering risk of ovarian cancer. A healthy diet was the most frequently cited way to reduce cancer risk (n=9), followed by exercise (n=7), avoiding alcohol (n=5) and not smoking (n=3).

## Decision-Making Needs and Resources

**Access to information**—Women cited several sources of information regarding RRSO, including literature, the internet, advocacy groups, family members and friends. Some

turned to their health care providers, but several reported difficulty getting information from them, especially about sexual side effects, which were seen as a taboo subject.

“I think women want to know, and ... nobody wants to talk about it. They [the doctors] feel funny about it.”

**Access to other women who have faced similar decisions**—The kind of information women reported receiving from their health care provider was variable and not necessarily considered trustworthy. On the other hand, women were consistently interested in hearing from other women facing similar situations, particularly the decision about RRSO. They wanted to hear about both positive and negative aspects of RRSO so that they could be comfortable with whatever decision they made.

“...something that would help would be to talk to other women in a forum type situation where maybe some women have gone through it and some women who are in the same place of considering it, so that the discussion and the dialogue can kind of move you to a place where you feel comfortable with whichever decision you make.”

Interest in this type of support was often couched in terms of establishing an ongoing relationship with other women and the health care system. This supports the concept that genetic risk assessment and counseling is a process that has several stages, and should not occur at a single point in time.

## Discussion of Main Points

Our data has identified both a need for more concrete information about ovarian cancer, and more support in making their risk reduction decisions. These findings are consistent with self regulation theory (SRT) which states that effective response to a health threat is a function of both an accurate perception of the threat, and the perceived ability to engage in the recommended actions<sup>21</sup>. The women we interviewed articulated a need for information about the degree of risk conferred by a *BRCA1* or *BRCA2* mutation, and other risk factors for ovarian cancer. This is particularly important given the evidence that perceived severity of ovarian cancer, and the perceived benefits of RRSO are important predictors of RRSO uptake<sup>22</sup>. We found that the majority of women were very focused on the risks associated with their personal and family history of cancer, which formed the backdrop through which genetic risk information was interpreted. The strength of combined personal and familial experience with cancer often overshadowed the importance of the test result for individual women. For women who have had cancer or cared for a relative with cancer, additional cancer risk information, such as a genetic test result, may have relatively little impact on their risk perception<sup>19</sup>. This insight could have important implications for how counseling interventions are designed. We also found that information provided by the positive genetic test result was also clouded by the wide range of ovarian cancer risk estimates communicated by clinicians.

The interviews revealed confusion about the risk reduction options provided and concern about their ability to cope with the sequelae of surgical menopause. Women considering RRSO not only want information about the degree of protection afforded by RRSO, but also about the practical and logistical aspects of the different surgical procedures, including the barriers of time missed from work, concerns about caring for children and other family members, and inadequate support after the surgery<sup>17</sup>. Fear of coping with physiologic and psychosocial menopausal side effects, generated the greatest source of reluctance about RRSO among these women and illustrated their lack of confidence in their ability to make this decision. This finding is consistent with a systematic review of risk reducing strategies

among women with hereditary breast and ovarian cancer syndromes, which found that the most commonly cited concerns about proceeding with RRSO were surgically induced menopause, the decision to use HRT, acceleration of the aging process, and psychosocial side effects of menopause<sup>23</sup>. Ray et al.<sup>24</sup> found that uncertainty about early menopause and concerns about HRT led to indecision about and avoidance of RRSO. These concerns are especially important given the wealth of data linking health behaviors to perceived benefits and perceived self-efficacy<sup>25, 26</sup>. In keeping with the SRT, a woman's level of confidence in her ability to cope with menopausal symptoms may influence her decision to pursue RRSO, and has implications for the counseling session.

The interviews have provided insights not only on the need for information and support, but also on the format of the information desired. Although women agreed that a great deal of information was provided to them during genetic counseling, many acknowledged that the overwhelming nature of the sessions and their emotional state at the time of disclosure interfered with knowledge retention. They suggested additional time and other sources of information to help them process the information and cope with their decisions. The women in our study articulated a desire to hear all sides of the issue, specifically the pros and cons of the surgery as experienced by other women. Exposure to other women's stories, in person or through social networking tools, along with professional assistance, could provide complimentary resources in the counseling process.

Our findings have direct relevance to the practice of genetic risk counseling and management. We identified the need for the cancer risk counseling team to provide evidence-based estimates of ovarian cancer risk, clearly explain the basis for risk estimates, and fully explore and incorporate each individual woman's personal and family experiences into the counseling process. Utilization of the widely available risk prediction tool, BRCAPRO, which incorporates age, gender, ethnicity, family history (first and second degree relatives on both maternal and paternal sides) breast cancer status and, for women with a diagnosis of breast cancer, marker status (ER, PR, Her2/neu), can help to provide more realistic estimates of ovarian cancer risk<sup>27</sup>. Women considering their RRSO options are likely to benefit from having the technical details of the available types of surgical approaches described, with graphical representations of ovarian anatomy and the importance of removing the fallopian tubes. Providing detailed information about the spectrum of menopausal side effects, their likelihood, and management strategies would also be valuable in the decision making process. Using the model of nurse navigators, nurse counselors can provide support and access to other resources by walking patients through the impact of scheduling their surgery on job responsibilities, child care and other family responsibilities, and by identifying appropriate other support, including their gynecologist, primary care practitioner or patient advocates. While usually thought of in the context of cancer treatment, support groups for women considering RRSO for ovarian cancer risk, led by a trained professional, is another example of responding to this need.

In summary, our challenge as genetic risk assessment professionals is to assist women in navigating this journey, provide the needed information and tools to facilitate personalized quality decisions. We have identified several areas where information gaps exist, and suggest some ways to provide the information and other forms of support. These findings will help to inform a web-based decision support tool that will be evaluated in the genetic counseling setting for its ability to address these gaps, address areas of uncertainty, guide women to additional resources, and improve the quality of the decision made. Other research directions include the development of interventions to assist partners and other caregivers support women confronting this decision, and the development of educational materials to help health care practitioners identify women who potentially have a hereditary risk for breast/ovarian cancer and to direct them to appropriate genetic services.

## Limitations

There are limitations to the current study. The sample size is small, especially among the younger women, and composed of mostly highly educated women. However, the demographics are representative of women who seek genetic testing for their risk of ovarian cancer, who have been primarily Caucasian, well educated women with a known family history of breast and/or ovarian cancer. The information gathered is retrospective and relied on the participant's recall of her experiences in considering prophylactic surgery. Confirmation of the importance of these findings should be confirmed in a prospective setting.

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**Table 1**

## Content Areas of Semi-Structured Telephone Interviews

1) The general meaning of a positive test result
2) The influence of the test result on self-perceived ovarian cancer risk
3) Other factors that are perceived to influence ovarian cancer risk
4) Ovarian cancer risk reduction options, including considerations of the type and timing of RRSO
5) Potential side effects of RRSO and options for management of those side effects
6) Decision-making needs and decision support regarding RRSO
7) Understanding uncertainty surrounding cancer risk estimates and the effectiveness of RRSO
8) Strategies for coping with these uncertainties

**Table 2**

Major Themes and Categories in Ovarian Cancer Risk and Risk-Reducing Strategies (n = 12)

Major Theme	Category
Perception of ovarian cancer risk	Risk associated with genetic test result Risk associated with personal and family history Information gaps Areas of fear and uncertainty
Understanding risk-reduction options	Type of prophylactic surgery Timing of surgery Other factors
Decision-making needs and resources	Access to information Access to other women who have faced similar decisions