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Award Number: DAMD17-00-1-0355

TITLE: Decision-making Regarding Prophylactic Mastectomy and Oophorectomy in Ashkenazi Jewish Women Seeking Genetic Testing for BRCA1/BRCA2 Mutations

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REPORT DATE: July 2001

TYPE OF REPORT: Annual Summary

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

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REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 074-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

1. AGENCY USE ONLY (Leave blank)	2. REPORT DATE	3. REPORT TYPE AND DATES COVERED
	July 2001	Annual Summary (1 Jun 00 - 1 Jun 01)

4. TITLE AND SUBTITLE

Decision-making Regarding Prophylactic Mastectomy and Oophorectomy in Ashkenazi Jewish Women Seeking Genetic Testing for BRCA1/BRCA2 Mutations

5. FUNDING NUMBERS

DAMD17-00-1-0355

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8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)

U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

10. SPONSORING / MONITORING AGENCY REPORT NUMBER

20011130 022

11. SUPPLEMENTARY NOTES

12a. DISTRIBUTION / AVAILABILITY STATEMENT

Approved for Public Release; Distribution Unlimited

12b. DISTRIBUTION CODE

13. Abstract ***(Maximum 200 Words)*** *(abstract should contain no proprietary or confidential information)*

Among women of Ashkenazi Jewish (Eastern European) descent, carriers of one of the three most common BRCA1/2 mutations have a 40-73% chance of breast cancer by the age of 70 and a 6-28% chance of ovarian cancer.[1] Few options exist for primary prevention of these cancers other than prophylactic surgery, or surgical removal of noncancerous organs in order to prevent occurrence of the disease. The primary aim of the study is to describe the levels of intention to undergo prophylactic mastectomy and/or oophorectomy among Ashkenazi Jewish women seeking genetic testing for inherited founder BRCA1 and BRCA2 mutations, and to identify factors that influence decision-making about prophylactic surgery. To achieve these aims, 611 women undergoing genetic counseling and testing for inherited breast ovarian cancer risk will be assessed before their first genetic counseling session and three times in the year following notification of their genetic test results. Major accomplishments during the past year include establishing collaboration with parent study, completing all pre-recruitment tasks, and publishing a peer-reviewed article and abstracts related to the study. Identifying factors relevant to decision-making about prophylactic surgery following genetic testing is critical to the design of counseling and informed consent protocols.

14. SUBJECT TERMS

breast cancer

15. NUMBER OF PAGES

51

16. PRICE CODE

17. SECURITY CLASSIFICATION OF REPORT	18. SECURITY CLASSIFICATION OF THIS PAGE	19. SECURITY CLASSIFICATION OF ABSTRACT	20. LIMITATION OF ABSTRACT
Unclassified	Unclassified	Unclassified	Unlimited

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Introduction

Among women of Ashkenazi Jewish (Eastern European) descent, carriers of one of the three most common BRCA1/2 mutations have a 40-73% chance of breast cancer by the age of 70 and a 6-28% chance of ovarian cancer.[1] Few options exist for primary prevention of these cancers other than prophylactic surgery, or surgical removal of noncancerous organs in order to prevent occurrence of the disease. Studies of women undergoing testing indicate a high degree of interest in both prophylactic mastectomy and prophylactic oophorectomy.[2-3] However, few studies have examined decision-making about whether to undergo these procedures.[4-6] Understanding the factors that contribute to decisions about surgery is important to the design of counseling and informed consent interventions, because more women will face this decision as genetic testing becomes more widely available. Also, studies that examine prophylactic surgery following BRCA1/2 testing have been done with women with a known mutation in the family, such that a negative result was a "true negative." A recent study of Ashkenazi women showed that 79% of women with a history of breast cancer and 35% of women with a combined family history of breast/ovarian cancer are not accounted for by one of the three founder mutations.[7] This represents a large number of women who need to be counseled about risk management without conclusive genetic information. Unfortunately, no study to date has examined levels of interest in prophylactic surgery in these women.

The present study is guided by stage theory, which proposes that people pass through a series of progressively more committed stages in the course of changing a health behavior.[8-9] This framework will allow us to distinguish levels of interest in surgery; i.e., between those choose to undergo prophylactic surgery from those who are contemplating the procedure but do not carry out their intention. The specific aims of the study are: 1) to describe the levels of intention to undergo prophylactic mastectomy and/or oophorectomy among Ashkenazi Jewish women seeking genetic testing for inherited founder BRCA1 and BRCA2 mutations; 2) to determine the relative contributions of sociodemographic, medical, and psychosocial factors to decision-making regarding prophylactic mastectomy and/or oophorectomy; and 3) to explore whether intentions to undergo prophylactic surgery change over time and to identify predictors of changes in intention. To achieve these aims, 611 women undergoing genetic counseling and testing for inherited breast ovarian cancer risk will be assessed before their first genetic counseling session and three times in the year following notification of their genetic test results.

Body

Collaboration with a new parent study has been established through Dr. Heiddis Valdimarsdottir, one of the mentors for this postdoctoral award. This switch was necessary because the parent study on which this study was originally to be based has closed, and the PI (Dr. Christine Eng) has moved to another institution. Dr. Valdimarsdottir is the Mt. Sinai PI for a multi-site study which, like the original parent study, involves genetic counseling and testing for BRCA1 and BRCA2 mutations in women with a family history of breast and ovarian cancer. Dr. Valdimarsdottir and Dr. Marc Schwartz from Georgetown University (project PI) have agreed to collaborate with the present study (see attached Letter of Support) and their project will serve as the new parent study. We will be able to carry out all of the proposed aims and analyses for the present study within the context of the new parent study.

In establishing the collaboration between the present study and the new parent study, all pre-recruitment tasks described in the Statement of Work, Tasks 1a-e, have been accomplished. The study measures have been revised to fit the protocol of the parent study and are fully incorporated into the parent study. A recruitment script has been written. IRB approval for the original protocol has been obtained. A revision to the protocol has been submitted for IRB approval to accomodate changes necessitated by the switch in parent study (see attached memo). A participant tracking system has been created using Access. A statistical database has been created in SPSS.

The primary goal of the new parent study is to conduct a randomized clinical trial of a CD-ROM decision aid for BRCA1/2 mutation carriers. The decision aid is designed to help mutation carriers decide on a risk management strategy (prophylactic mastectomy vs. intensive mammography screening vs. Tamoxifen plus mammorgraphy). All participants receive a pre-test genetic counseling session, and those who choose to undergo testing donate a blood sample. Test results are given in a notification counseling session with the genetic counselor. All participants also undergo telephone interviews (once before the pre-test genetic counseling session, and at several timepoints following notification of their genetic test results). Those who test positive for a BRCA1/2 mutation are then randomized to receive either a) a CD-ROM decision aid to supplement standard genetic counseling or b) continue with standard genetic counseling as usual. Parent study participants who are mutation carriers and who are randomized to receive the CD-ROM intervention will not be eligible for the present study because the intervention is targeted at one of the main outcome variables (interest in prophylactic mastectomy). All other participants (those who test negative, and mutation carriers who are randomized to receive only standard genetic counseling) are eligible for the present study.

The new parent study is larger in scope than the original parent study. Recruitment for the new parent study has begun and 228 women have been enrolled. The current pace of enrollment in the parent study is approximately 45 participants per month. Enrollment

efforts will increase once the CD-ROM to be used in the intervention for the parent study has been completed. Recruitment plans at Mt. Sinai include contacting gynecologic oncologists to enroll ovarian cancer patients, and advertising in local newspapers aimed at the Ashkenazi Jewish community (The Forward, Jewish Week, and The Jewish Post). Because the measures for the present study overlap with the parent study, women who have already received counseling and testing can be enrolled in the present study by obtaining consent to retrospectively include their responses to the parent study telephone interviews that have already been conducted. Counting in the women already enrolled in the parent study, we will need an average enrollment of 29 participants per month to achieve the recruitment goal of 611 participants for the present study. Extrapolating from current efforts and plans, this goal can be readily achieved.

Of the women in the parent study who have undergone genetic testing thus far, 32% are BRCA1 or BRCA2 mutation carriers, 19% are true negatives and 49% are negative/inconclusive (compared to projected figures from the original parent study of 13%, 7% and 80% respectively). This increase in the proportion of mutation carriers reflects recruitment strategies aimed at maximizing the number of carriers who would be eligible for randomization to the intervention in the parent study. From a data analysis standpoint, this is an advantage for the present study, because cell sizes will be more balanced, giving us more statistical power to detect differences in levels of interest in prophylactic surgery and on other study variables (e.g., distress) based on mutation status.

The parent study is open to both Ashkenazi Jewish women and women of other ethnicities. Fifty-seven percent of those currently enrolled in the parent study are of Ashkenazi Jewish descent. The large proportion of Ashkenazi women in the parent study will permit us to fulfill the study aim to describe levels of interest in prophylactic surgery in this population. Opening the present study to non-Ashkenazi women is advantageous because it will permit us to conduct analyses exploring whether there are differences in interest in prophylactic surgery, pros and cons of surgery, levels of distress, etc. based on ethnic background which may be helpful for genetic counselors and other health provideders to be aware of .

Key Research Accomplishments

1. Established collaboration with new parent study.

2. Revised measures for compatability with parent study protocol.

3. Submitted IRB paperwork for revisions to protocol and informed consent form based on new parent study.

4. Developed participant tracking system using Microsoft Access database.

5. Created statistical database in SPSS

6. Developed recruitment strategies to enroll participants from target population (women of Ashkenazi Jewish descent with a family/personal history of breast and/or ovarian cancer).

7. Published journal article on related topic; completed second manuscript to be submitted.

8. Submitted abstracts to national conferences (one of which has already been presented).

Reportable Outcomes

In keeping with the professional development goals of the postdoctoral award, the PI has published an article in a peer-reviewed journal and presented at a national conference on the topic of women at familial risk for breast and ovarian cancer. These activities, supported by the post-doctoral award, will help the PI establish herself as an independent investigator in breast cancer research.

1. Peer reviewed article. The lead editorial in the same issue featured the article, calling attention to the need for further research on decision-making about prophylactic surgery. (see attached)

Hurley K, Miller S, Costalas J, Daly M. Anxiety/uncertainty reduction as a motivator for interest in prophylactic oophorectomy in women with a family history of ovarian cancer. Journal of Women's Health and Gender-Based Medicine. 2001;10:189-199.

2. Conference poster presentation. (see attached abstract)

Hurley, K., Valdimarsdottir, H., Brown, K., Stravinski, L., & Eng, C. (2001). Coping strategies and interest in prophylactic surgery. Poster presented at The Society of Behavioral Medicine Twenty-Second Annual Scientific Sessions, Seattle, WA, March, 2001.

3. Manuscript in preparation. Preliminary results on which this article is based were presented by the PI at a lecture at Fox Chase Cancer Center in May 2001 (see attached MSS).

Hurley K, Miller S, Gillespie D, Daly M. The price of vigilence: The impact of monitoring and beliefs about cancer prevention on distress among women at familial risk for ovarian cancer. (in preparation).

4. Abstract submitted. (see attached abstract)

Hurley, K., Valdimarsdottir, H., Brown, K., Rispoli, J., Stravinski, L., McGlynn, J., Grant, D., & Eng, C. (2001). Intrusive ideation about cancer risk before and after BRCA1/2 mutation testing.

Conclusions

Two main outcomes have been achieved thus far. First, a collaboration with a new parent study has been established, following the closing of the original parent study. A considerable amount of work has been done to ensure that recruitment, informed consent procedures, measures, assessment schedules, and data management flow smoothly between the two studies. Second, the PI of the present study has published an article and submitted two abstracts on the topic of women at familial risk for breast and ovarian cancer, furthering her development as an independent researcher in this field. The present study addresses important gaps in the research literature on prophylactic surgery. First, the present study is designed to examine psychosocial factors that are likely to influence the decision. Second, there are no published longitudinal studies of interest in prophylactic surgery. The proposed study employs a prospective design to evaluate changes in levels of interest in surgery for up to a year following notification of genetic test results. Identifying factors relevant to decision-making about prophylactic surgery following genetic testing is critical to the design of counseling and informed consent protocols. Third, this study provides a template for studying the management of breast cancer risk in the context of other cancers for which inheritance is shared, which will be necessary as additional clusters of inherited cancers are identified. Lastly, the present study employs stage theory, which will permit the design of state-of-the-art, stage-matched interventions based on our results.

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Appendices

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6. Curriculum vita for Marc Schwartz, Ph.D., Prinicipal Investigator for the parent study of this project. A letter of support will be sent under separate cover.

JOURNAL OF WOMEN'S HEALTH & GENDER-BASED MEDICINE
Volume 10, Number 2, 2001
Mary Ann Liebert, Inc.

Anxiety/Uncertainty Reduction as a Motivation for Interest in Prophylactic Oophorectomy in Women with a Family History of Ovarian Cancer

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ABSTRACT

Most women at familial risk for ovarian cancer must decide about prophylactic oophorectomy without conclusive genotypic information about their risk level. Some women with relatively low-risk profiles seek prophylactic oophorectomy or are recommended the procedure by their physicians, if they appear "cancerphobic." This study investigated the desire to reduce anxiety in relation to other factors associated with interest in prophylactic oophorectomy in a group of women with varying degrees of familial risk for ovarian cancer. Ninety-four women enrolled in an ongoing program for women with a family history of ovarian cancer received personalized risk counseling and were classified as having a sporadic, familial, or putative hereditary pedigree by a genetics counselor. Eligible enrollees were interviewed by telephone about current and future interest in prophylactic oophorectomy, perceived risk of ovarian cancer, severity of cancer anxiety, stress-related ideation, and reasons for and against surgery. Reduction of anxiety/uncertainty was the factor most strongly associated with current interest in prophylactic oophorectomy, independent of objective risk classification, perceived risk, severity of cancer anxiety, intrusive ideation, or other variables. Future interest in prophylactic oophorectomy was predicted by other perceived benefits of surgery. Current, but not future, interest in prophylactic oophorectomy appears motivated in part by seeking immediate relief from anxiety. Interest in prophylactic oophorectomy may fluctuate based on varying exposure to cues that trigger anxiety. Women seeking prophylactic oophorectomy, particularly those with lower-risk family pedigrees, should be offered options for anxiety management as part of informed consent for prophylactic oophorectomy.

INTRODUCTION

WOMEN WITH A FAMILY HISTORY of ovarian cancer face a number of difficult decisions because of their increased risk for developing the disease.[1] The situation is particularly threatening for them because of the relatively low survival rates associated with ovarian cancer,[2] compounded by the degree of uncertainty entailed in the few choices for risk management that are

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Preparation of this paper was supported in part by ACS grant PBP-89318, DOD grants BC971638 and OC970004, NIH grants CA81137, CA58999, CA61280, CA06927, HG01766, R01HG01189, and U01CA69631, the Dyson Foundation, and appropriations from the Commonwealth of Pennsylvania.

available. For example, the screening tests typically used to screen for ovarian cancer (transvaginal ultrasonography and blood testing for the tumor marker CA-125) fall short in sensitivity and specificity compared with screening tests used to detect other gynecological cancers.[3,4] Although chemoprevention is associated with reduced risk of ovarian cancer,[5,6] the main preventive option available at present is bilateral prophylactic oophorectomy, or surgical removal of noncancerous organs in order to prevent occurrence of the disease.

Perhaps it is not surprising, given the circumstances, that the few studies to date on decision making about prophylactic surgery indicate that anxiety and intrusive thoughts about developing cancer play a key role in the decision-making process.[7,8] In fact, anxiety is viewed by some medical practitioners as an indication for surgery, who may recommend the procedure to a patient if she appears "cancerphobic" even if she does not have a marked family history.[9,10] Treating a woman's anxiety about cancer through prophylactic surgery incurs medical consequences, both through the immediate impact of surgery and its risks and through the long-term effects of surgical menopause.[11] Furthermore, prophylactic oophorectomy may not provide complete relief from anxiety because the literature to date suggests that the procedure substantially reduces, but does not completely eliminate, a woman's risk of ovarian cancer.[12–14]

Anxiety can also have a negative impact on ability to give informed consent to prophylactic oophorectomy. High levels of anxiety and stress-related ideation have been shown to interfere with ability to recall threat-related information.[15] If a woman is distressed about her risk for cancer to the extent that she cannot recall important information related to her decision, her desire for immediate relief short-circuits a full consideration of the implications of undergoing prophylactic oophorectomy, such as residual risk for peritoneal cancer and the need to weigh the benefits and risks of hormone replacement therapy (HRT).[16,17]

Individuals will differ in the level of anxiety engendered by their risk status and how heavily they weigh anxiety compared with other factors bearing on their decision.[18] The research on adjustment to ovarian and breast cancer risk suggests that approximately 15%–25% of women with a family history of cancer are highly anxious about their chances of developing the disease and experience repeated intrusive thoughts about their risk, to the extent that it interferes with daily activities.[19,20] This represents a sizable group of women who may seek prophylactic oophorectomy primarily for management of their anxiety.

Some of the uncertainty that makes familial risk for ovarian cancer so anxiety provoking will be eased as genetic testing for specific inherited mutations associated with increased susceptibility to ovarian cancer becomes more comprehensive and widely available. At present, however, the mutations identified thus far that are linked to ovarian cancer risk account for only an estimated 40%–50% of cases in women with two or more affected relatives.[21,22] As a result, even with genetic testing, many women must make decisions about prophylactic oophorectomy in the absence of conclusive genotype information. This group also includes women who do not have access to genetic testing because of financial or other barriers.

For those who must make a decision about prophylactic oophorectomy on the basis of pedigree information alone, some estimate of risk can be made on the basis of family history (e.g., number of affected relatives, mixed ovarian/breast pedigree, age of onset).[23] Nonetheless, research has shown that many women with a family history of cancer overestimate their level of risk,[20,24] and these inflated estimates are resistant to modification even after individualized risk education based on review of the family pedigree.[24–27] Therefore, it is important to determine the role of anxiety and perceived risk in decision making about prophylactic oophorectomy relative to objective risk factors in order to help women come to a decision that balances concerns about their long-term physical and psychological well-being.

We conducted our study to determine levels of interest in prophylactic surgery among women with varying degrees of familial risk for ovarian cancer who have not undergone genetic testing and to explore anxiety reduction as a motivating factor for considering prophylactic surgery in the context of other factors, including family pedigree information, perceived risk, and cancer-related intrusive thoughts. We also examined the relative weight of desire to reduce anxiety about cancer in relation to other factors identified in the literature as influential in women's decision making about prophylactic oophorectomy, including childbearing, reducing one's risk, fears about the

risks of surgery, worries about menopause and HRT, beliefs about the efficacy of prophylactic oophorectomy, and identity issues.[7,8,28] Our predictions were that there would be a wide range in levels of interest in prophylactic surgery, that there would a subgroup of women who were highly distressed about their risk, and that desire to reduce anxiety would be strongly associated with interest in prophylactic surgery, independent of familial risk classification and other psychosocial factors.

PATIENTS AND METHODS

Overview and background

The present study is part of a larger, ongoing clinical research effort being conducted with women who have a family history of breast or ovarian cancer or both through the Family Risk Assessment Program (FRAP) at Fox Chase Cancer Center in Philadephia, PA. FRAP participants with a family history of at least one relative with ovarian cancer were invited to complete an interview on prophylactic ovarian surgery as a supplement to their regular, ongoing participation in FRAP. The present study combined a subset of baseline data previously collected from participants on entry into FRAP with data collected during the prophylactic oophorectomy telephone interview developed specifically for this study.

FRAP was founded in 1991 for women over the age of 25 with at least one first-degree relative (mother, sister, daughter) with breast or ovarian cancer. Initially, women were recruited by contacting relatives of patients being treated for breast or ovarian cancer at Fox Chase Cancer Center. Participants are now also self-referred or are referred by their physician. After enrolling, FRAP participants attend a 2-hour small group education session on breast and ovarian cancer risk and on the roles of cancer screening and preventive surgery in risk management. Nutritional assessment and dietary recommendations also are made. Each woman meets individually with a genetics counselor, who reviews the woman's family history and provides a personalized risk estimate. Women are instructed in breast self-examination and are offered screening tests, including mammography, transvaginal ultrasonography, and CA-125 testing at the Fox Chase Cancer Center facilities.

Procedure

FRAP participants with at least one first-degree relative with ovarian cancer and who had been enrolled in FRAP for at least 1 year were notified by letter that a study was being conducted to obtain additional detail on levels of interest in prophylactic surgery among FRAP participants. The letter stated that they would receive a telephone call inviting them to participate in a short, 15-minute interview. Informed consent was obtained in writing and over the phone. Women who agreed to participate in the proposed study were interviewed by phone by the first author or another graduate level clinical interviewer using the measures listed below.

Baseline measures

The following information was drawn from the FRAP database. These measures were collected on the participant's entry into FRAP at least 1 year before the present study.

Demographics. Age, ethnicity, marital status, education level, number of children, and menopausal status were elicited

Objective risk of cancer. A participant's family history was categorized as high, moderate, or low risk by a medical genetics counselor from Fox Chase Cancer Center. Putative hereditary indicates that there were two or more cases of ovarian cancer (any age) on one side of the family or one ovarian cancer plus one breast cancer on the same side of the family diagnosed at age 50 or younger.[29] Familial describes the presence of one case of ovarian cancer diagnosed at age 50 or younger or one case of ovarian cancer (any age) plus one or more cancers at various sites (e.g., breast, uterus, pancreas, stomach, colon)[30,31] on the same side of the family. If breast cancer was present, there was no more than one case, and it was diagnosed over the age of 50. Sporadic indicates one case of ovarian cancer occurring after age 50. If other cancers were present on the same side of the family, they have not been reported in conjunction with familial ovarian cancer (e.g., skin, lung).

In cases where a participant had a history of cancer on both paternal and maternal sides of her family, she was assigned to the higher risk category (e.g., if the mother's side shows hereditary (high) risk and the father's side shows sporadic

(low) risk, the participant is assigned to the hereditary category).

Interview measures

The following measures were collected in the telephone interview.

Interest in prophylactic ovarian surgery. Levels of interest were assessed with two questions: At this time how strongly are you considering prophylactic surgery? (current interest), and How likely is it that you will have surgery someday? (future interest), each of which was measured on a 5-point scale (1, not at all; 5, very strongly/definitely). Participants who rated their interest as <5 were asked if they had considered surgery more strongly in the past and indicated their past interest on a similar 5-point scale.

Perceived risk of developing ovarian cancer. Participants estimated their personal level of risk on a scale of 0–100.

Stress-related ideation. We used the intrusive ideation subscale of the revised Impact of Events Scale (RIES).[32] This seven-item measure assesses intrusive thoughts, images, dreams, and distress at reminders of a specified stressor. For the present study, participants were asked to respond to each item with respect to their familial risk for ovarian cancer. This instrument has been validated by other researchers for the assessment of threat-related ideation in patients at risk for cancer.[19,33,34] Participants rate the frequency of symptoms on a weighted 4-point scale (0, not at all; 1, rarely; 3, sometimes; 5, often). Scores can range from 0 to 35. Internal reliability of the scale has been shown to be 0.84 in individuals at familial risk for cancer.[35]

Severity of cancer anxiety. Participants were asked to rate how anxious they became when they thought about ovarian cancer on a single 5-point item (1, not at all; 5, extremely).

Pros and cons of oophorectomy. Participants rated four reasons in favor of surgery and seven reasons against surgery on a 5-point scale (1, not at all; 5, completely) for how heavily each weighed in the woman's thinking about surgery. Participants were also asked to identify one factor that was the most important weighing in favor of and against surgery. Items were developed based on the literature about issues related to prophylactic oophorectomy[7,8,28] and on women's reports about their concerns. To investigate the role of anxiety reduction as a motivation for surgery, we divided the pros scale into two components, anxiety-related and other benefits of surgery, creating composite scores for each component. There were two anxiety-related items (Surgery would give me relief from fear of getting cancer; Having surgery would reduce the amount of uncertainty in my life) with a Cronbach's alpha of 0.89. The other four items (I don't want to keep getting screening tests; Ovarian cancer is difficult to detect early, when it is easier to treat; I need to feel like I'm taking steps to prevent cancer; and My physician recommended I have surgery) together have a Cronbach's alpha of 0.71. The cons showed low internal consistency ($\alpha = 0.41$), reflecting that barriers varied from person to person. Thus, rather than create a composite score, we conducted the analyses using the individual barrier items (see ref. 36 for a similar treatment of barriers to and benefits of mammography).

Efficacy of prophylactic surgery. Belief in the efficacy of prophylactic oophorectomy was assessed by a single 5-point item (1, not at all; 5, completely): How effective is prophylactic surgery in preventing ovarian cancer?

Childbearing. Desire to have children or complete one's family was scored on a single, dichotomous variable.

Participants

Participants in the present study were women over the age of 25 with at least one first-degree relative (mother, sister, daughter) with ovarian cancer. As of January 1997, 160 eligible women completed the educational component and 1 year follow-up. Of these 160 women, 1 had moved out of the area and been terminated from the program, 2 had voluntarily opted out of the study, and 1 was deceased, leaving a total of 156 potential participants for the present study.

Of these 156, 6 could not be contacted because the address or phone number was out of date, and 39 could not be reached before the end of the study. Of the 111 women who were contacted by phone, 3 declined to participate. One woman was excluded because she stated that she had never

heard of prophylactic surgery and was unable to answer the questions in the interview. Thirteen of the women reached had already undergone prophylactic ovarian surgery. These women were excluded from the analysis because their attitudes and levels of anxiety could only be assessed retrospectively, whereas we were interested in linking current attitudes and levels of anxiety with current levels of interest in prophylactic surgery. The final sample consisted of 94 women.

RESULTS

Description of the sample

Participants ($n = 94$) had been enrolled in FRAP for an average of 3.7 years (SD 1.1, range 1.3–5.6) prior to being interviewed for this study. Eighteen (19.1%) were classified as having a family history that consisted of sporadic cases of cancer. Forty-two women (44.7%) were classified as having a familial pattern, and 34 (36.2%) had a history consistent with a hereditary pattern. The mean age of participants was 40.27 years (SD 9.87). The majority of the participants were married (81.9%), and all but 1 were Caucasian. Three-quarters of the women had attended college or beyond. Sixty participants (63.8%) had at least one child. Eighty (85.1%) of the women were still menstruating, and of those, 17 (18.1%) were interested in having a child (or another child). Ten of these 17 had not yet had a child.

Levels of current and future interest in prophylactic oophorectomy

Forty-nine of the women in the study (52.1%) stated that they were not considering surgery at all at this time. One quarter of the sample (26.6%) were considering surgery somewhat, and just under one quarter were considering surgery at least moderately (Table 1). A different picture emerges when the participants were asked about their interest in pursuing surgery in the future. Slightly less than one third (31.9%) reported that it was not at all likely that they will undergo surgery. Over one third (35.1%) reported that they had some intention of having surgery, and one third (32.9%) reported that their intentions were at least at a moderate level (Table 1). None of the demographic variables or length of participation in FRAP was associated with current or future interest in surgery. Of the 49 participants reporting that they were not currently considering prophylactic ovarian surgery, 20 stated that they had been considering surgery more strongly in the past. Half of those reporting that they had changed their mind had at one time been considering surgery very seriously.

TABLE 1. FREQUENCIES OF CURRENT AND FUTURE INTEREST IN PROPHYLACTIC OOPHORECTOMY

	Current interest (%)	*Future interest (%)*
Not at all	49 (52.1)	30 (31.9)
Somewhat	25 (26.6)	33 (35.1)
Moderately	9 (9.6)	16 (17.0)
Very	9 (9.6)	10 (10.6)
Extremely	2 (2.1)	5 (5.3)

Stress-related ideation and anxiety. The mean RIES intrusive ideation score was 4.43 (SD 6.64). Six participants (6%) appeared highly distressed, with RIES intrusion scores of ≥18. Eleven participants (12%) reported moderate to severe intrusive ideation (scores of 10–17), and 39 (42%) reported low to moderate levels of intrusive ideation (scores of 1–9). Thirty-seven participants (40%) reported no intrusive ideation during the past week. Because of the large proportion of participants reporting no intrusive ideation, we dichotomized the scores into none versus any intrusive ideation. Using this score, intrusive ideation was positively related to both current ($\chi^2 = 6.4$, $df = 3$, $p < 0.04$) and future interest ($\chi^2 = 6.16$, $df = 3$, $p < 0.04$) in surgery. Almost half of the participants reported that when they do experience anxiety about the possibility of developing ovarian cancer, they become quite or extremely anxious. Only 15 reported they experience little or no anxiety. Severity of cancer anxiety was not related to either current interest, $F(2,91) = 1.31$ (NS) or future interest, $F(2,91) = 0$ (NS) in prophylactic oophorectomy.

Perceived risk. Estimates of perceived risk ranged from 0 to 100, with a mean of 38.43 (SD 25.05). Perceived risk was correlated with severity of cancer anxiety ($r = 0.22$, $p < 0.03$) and marginally with intrusive ideation (Spearman's rho = 0.16, $p < 0.07$). Perceived risk was positively associated with current interest in surgery, $F(2, 90) = 3.84$, $p < 0.02$, such that those who

were very/extremely interested in surgery had higher levels of perceived risk than those who were not interested in prophylactic oophorectomy. Perceived risk was not related to future interest in prophylactic oophorectomy, $F(2,90) = 1.89$ (NS).

Perceived efficacy of surgery. Twelve (12.8%) of the women believed that prophylactic oophorectomy was completely effective in preventing ovarian cancer. Perceived efficacy of prophylactic oophorectomy was marginally associated with current interest in prophylactic oophorectomy, $F(2,91) = 2.81$, $p < 0.06$, such that those who had any interest in surgery perceived prophylactic oophorectomy to be more effective in preventing ovarian cancer than those who had no interest. Perceived efficacy of surgery was not related to future interest in prophylactic oophorectomy.

Familial risk level and its influence on interest in prophylactic surgery and psychosocial variables. There was no difference among the three familial risk groups in terms of considering prophylactic surgery at present ($\chi^2 = 6.78$, $df = 5$ [NS]) or likelihood of having surgery someday ($\chi^2 = 2.66$, $df = 5$ [NS]). There was no difference between the three familial risk groups on intrusive ideation ($\chi^2 = 0.07$, $df = 5$ [NS]) or ovarian cancer anxiety, F (2,91) = 0.06 (NS). Participants in the three familial risk groups did not differ in perceived risk, F (2,88) = 1.50 (NS), or perceived efficacy of prophylactic oophorectomy, $F(2,93) = 1.10$ (NS).

Pros and cons of prophylactic surgery

Anxiety/uncertainty reduction as a motivation for surgery was associated with current interest in prophylactic oophorectomy, $F(2,91) = 21.00$, $p < 0.0001$. Those who were very or somewhat interested in surgery were more likely to endorse anxiety/uncertainty reduction as a benefit of surgery than those who were not interested. A similar relationship was observed between anxiety/uncertainty reduction and future interest in surgery, $F(2, 91) = 7.26$, $p < 0.001$. Desire to reduce anxiety/uncertainty was positively correlated with belief in the efficacy of prophylactic oophorectomy ($r = 0.28$, $p < 0.007$). Interestingly, 5 of 18 participants (28%) classified as having a sporadic family history ranked relief from fear/uncertainty as the most important reason in favor of surgery.

Other benefits of surgery were also associated with current interest in prophylactic oophorectomy, $F(2, 91) = 19.69$, $p < 0.0001$. Those not currently interested in surgery were less likely to rate benefits of surgery as weighing heavily in their decision than those who were somewhat or very interested. Benefits were also associated with future interest, $F(2,91) = 16.20$, $p < 0.0001$. Those who were very interested in having prophylactic oophorectomy someday were more likely to endorse benefits than those who were only somewhat interested, who in turn were more likely to endorse benefits than those who reported no future interest in prophylactic oophorectomy.

The only reason against surgery that was associated with current interest in surgery was risk of surgery $F(2,91) = 3.42$, $p < 0.03$, such that those who were not interested in surgery were more likely to be concerned about risks of surgery than those who were very interested in surgery. The only reason against surgery associated with future interest in surgery was concern about exposure of risk status to one's insurance company or employer, $F(2,91) = 5.41$, $p < 0.006$, such that those with a moderate future interest in surgery were more concerned about exposure of their risk status than those with no interest or strong interest.

Predictors of interest in prophylactic surgery

We used stepwise regression to examine predictors of current (Table 2) and future interest in surgery. For each outcome (current and future interest), the following independent variables were entered: family history, severity of cancer anxiety, intrusive ideation, perceived risk, reducing anxiety/uncertainty, and other benefits of surgery. In addition, risk of surgery was added for current interest, and exposure of risk status was entered for future interest. The model for current interest in surgery was significant, $F(3,87) = 22.79$. Reducing anxiety/uncertainty was the strongest predictor of current interest, accounting for 28% of the variance. Other variables entering the equation were risk of surgery and other benefits, accounting for an additional 9% and 5% of the variance respectively, for a total of 42%. The model for future interest (Table 3) in surgery was also significant, $F(1,89) = 28.25$, $p < 0.0001$. The variable, other benefits of surgery, was the sole variable that entered the equation, accounting for 24% of the variance.

TABLE 2. FACTORS ASSOCIATED WITH CURRENT INTEREST IN PROPHYLACTIC OOPHORECTOMY

	Association with current interest in prophylactic oophorectomy	p	*Factors retained stepwise in regression model*
Objective risk	$\chi^2 = 7.26$, $df = 5$		
Perceived risk	$F = (2,88) = 3.84$		
Intrusive ideation	$\chi^2 = 6.4$, $df = 3$	*	
Severity of cancer anxiety	$F(2,91) = 1.31$		
Perceived efficacy	$F(2,91) = 2.81$, $p < 0.06$	†	
Anxiety/uncertainty reduction	$F(2,91) = 21.00$	**	$r^2 = 0.28$
Other benefits of surgery	$F(2,91) = 19.69$	**	$r^2 = 0.05$
Risks of surgery	$F(2,91) = 3.42$	*	$r^2 = 0.09$
Concern about privacy	$F(2,91) = 1.81$		
Desire to have children (premenopausal women only)	$F(2,91) = 1.67$		

†$p < 0.06$ (marginal).
*$p < 0.05$.
**$p < 0.001$.

Menopausal status

Because childbearing is a crucial element in deciding about prophylactic oophorectomy, we conducted several analyses just among the women who had not yet undergone menopause. Premenopausal women who wished to have more children were younger, $F(1,81) = 48.28$, $p < 0.001$, had higher levels of perceived risk, $F(1,76) = 4.49$, $p < 0.04$, and had a marginally higher desire to reduce anxiety/uncertainty, $F(1,82) = 3.63$, $p < 0.06$, than those who had completed their families. The two groups did not differ in current interest in prophylactic surgery ($\chi^2 = 2.61$, $df = 3$ [NS]), future interest in prophylactic surgery ($\chi^2 = 2.04$, $df = 3$ [NS]), or any other study variables.

DISCUSSION

The results of the present study underscore the important role of anxiety in decision making about whether to undergo prophylactic oophorectomy in women with a family history of ovarian cancer. Among women in the sample who were currently considering prophylactic oophorectomy, the desire to reduce anxiety and uncertainty was the strongest predictor of interest in the procedure, independent of family history or perceived risk. Indeed, several women in the lowest-risk category had some of the highest levels of intrusive ideation about their risk of ovarian cancer and some of the strongest interest in prophylactic oophorectomy.

Although none of the women had undergone

TABLE 3. FACTORS ASSOCIATED WITH FUTURE INTEREST IN PROPHYLACTIC OOPHORECTOMY

	Association with future interest in prophylactic oophorectomy	p	*Factors retained stepwise in regression model*
Objective risk	$\chi^2 = 2.29$, $df = 5$		
Perceived risk	$F = (2,88) = 1.89$		
Intrusive ideation	$\chi^2 = 6.16$, $df = 3$	*	
Severity of cancer anxiety	$F(2,91) = 0.82$		
Perceived efficacy	$F(2,91) = 1.91$		
Anxiety/uncertainty reduction	$F(2,91) = 7.26$	***	
Other benefits of surgery	$F(2,91) = 16.20$	***	$r^2 = 0.24$
Risks of surgery	$F(2,91) = 1.43$		
Concern about privacy	$F(2,91) = 5.41$	**	
Desire to have children (premenopausal women only)	$F(2,91) = .70$		

*$p < 0.05$.
**$p < 0.01$.
***$p < 0.001$.

genetic testing at the time of the study, our results are applicable both to women who do not have access to testing (e.g., due to cost) and to the substantial proportion of women who undergo genetic testing who receive inconclusive results. Anxiety produces an interpretive bias that skews people to think of something ambiguous as threatening,[15] even if the information is tentative good news (e.g., no known mutation detected).[37] Indeed, in individuals undergoing diagnostic testing, receiving a tentative diagnosis of wellness (there is probably nothing wrong) has been shown to induce as much interest in being treated for a disorder as if they had actually been diagnosed with the disorder in question.[37] In the present study, desire to reduce anxiety/uncertainty was associated with higher perceived efficacy of prophylactic oophorectomy and, in some cases, with the erroneous belief that the procedure offers 100% protection from ovarian cancer. For women who are considering prophylactic oophorectomy as a means to relieve their anxiety about the possibility of developing ovarian cancer, a fully informed decision about whether to undergo prophylactic surgery should include information not only about medical risks and benefits but also about the nature of cancer-related anxiety and intrusive ideation, how anxiety and intrusive ideation affect decision making, and the availability of effective treatments for these psychological conditions.

Intrusive ideation about one's risk of cancer consists of repeated, unwanted thoughts about the disease that can take the form of thoughts, images, memories, or nightmares.[38] These thoughts can occur either unbidden or in response to cues and can be accompanied by physiological symptoms of anxiety, such as rapid heartbeat, sweating, and feeling of panic. Although the overall mean intrusive ideation score was low, 18% of the women reported levels of intrusive ideation in the moderate to severe range. This finding is consistent with reports in the literature that approximately 15%–25% of women at familial risk of cancer experience high levels of intrusive ideation about their risk for the disease.[19,20]

Theorizing about the psychological processes involving in coping with health threats suggests that repeated intrusive images about one's risk create a vivid focus on the threat of cancer, intensifying the desire for relief, which may override other factors that influence decision making about prophylactic oophorectomy.[18] The ability to neutralize this process by shifting attention away from vivid images of risk to a more abstract consideration of the issues may lead to a more informed, deliberate decision.[39] Consistent with this interpretation, we found that future interest in prophylactic oophorectomy, which by definition is more abstract and removed from the heat of the present moment, was predicted by such benefits as low perceived efficacy of ovarian cancer screening and physician recommendation but not by desire to reduce anxiety.

Other features of intrusive ideation are important to consider in counseling someone about coping with the risk of cancer. We found both quantitative and anecdotal evidence that intrusive thoughts about risk fluctuated over time and tend to increase in response to cancer-related cues. For example, one woman was interviewed on the exact anniversary date of her mother's death due to ovarian cancer, and her level of intrusive thoughts was extremely high. By contrast, another woman, an oncology nurse who was strongly considering surgery and who spoke at length about her general level of intrusive worry, had experienced few intrusive thoughts in the past week. She attributed her responses to having been off from work for the past 5 days, which meant that she had been exposed to few, if any, reminders of her risk. She stated that there have been other times when she was caring for three ovarian cancer patients with advanced disease at once. At those times, she experienced continuous intrusive thoughts about her personal risk level and about having surgery.

Exposure to cues that trigger intrusive, anxiety-provoking thoughts about cancer risk will vary considerably both from person to person and over time. Some reminders will occur predictably (e.g., anniversary of mother's death, annual screening appointment), and some will be unpredictable (e.g., having a friend diagnosed with cancer). Interest in prophylactic oophorectomy may rise and fall in response to such reminders. Several of the women remarked during the interview that they were strongly considering surgery during or immediately after their relatives' illness or death but that their interest in prophylactic oophorectomy subsided over time. Indeed, almost half of the women in the study who were not currently considering prophylactic surgery at all reported that they had considered it in the past. Therefore, counseling about prophylactic oophorectomy should include informa-

tion that both intrusive ideation and interest in surgery can change over time.

Research has shown that educational interventions that merely present factual information about familial risk of cancer appear insufficient to address anxiety and uncertainty about one's risk level.[25] Fortunately, empirical studies have demonstrated that effective, short-term therapy exists for the management of anxiety and intrusive ideation, including exposure therapy, systematic desensitization, and stress inoculation training.[40–43] An intervention designed to specifically address intrusive ideation and anxiety about ovarian cancer would include desensitization, education about the fluctuating nature of intrusive thoughts about one's risk, and cognitive-behavioral strategies for coping with anxiety triggers, such as the anniversary of a family member's death. The fact that in the final regression equation for current interest in prophylactic oophorectomy, desire to reduce anxiety/uncertainty was retained but that severity of anxiety and intrusive ideation were not may reflect that some women who experience distressing thoughts about their risk may have effective strategies they can use to cope with their distress. Identifying such strategies would be an important goal for future research.

A limitation of the present study is that it was conducted with women attending a clinic for high-risk individuals and may not represent women with a family history of ovarian cancer who do not seek out these services. However, the present sample does represent women who are educated about their risk level and who may come to doctors' offices with questions about prophylactic surgery. In addition, levels of interest in prophylactic oophorectomy and determinants of such interest may be different for women who undergo genetic testing and who know their mutation status. In our sample, half of the women in the sample were considering prophylactic oophorectomy at least somewhat at the time of the study, and two thirds did not rule out the possibility of undergoing the procedure in the future. These levels of interest are comparable to those in published reports of women from families in which the presence of a *BRCA1* mutation had been established.[44,45]

Another limitation of the present study is that the cross-sectional design does not show the process of adaptation to one's level of risk over time. A prospective study of changes in levels of interest in surgery over time would provide important additional information about how to manage counseling and informed consent procedures during these stressful junctures in the course of a lifetime of elevated risk by identifying the type and frequency of transition points when counseling about options would be needed most.

Targeted psychological interventions for cancer-related intrusive ideation and anxiety offer a less physically invasive option for women whose primary indication for prophylactic surgery is fear of cancer and may enhance full consideration of postsurgical implications for those with other indications for surgery, such as a strong family history. After undergoing a psychological intervention, such as those described, if a woman still wanted to undergo prophylactic oophorectomy, she may be in a better position to give informed consent. Strategies for coping with cancer-related intrusive ideation may also benefit those who are postponing prophylactic oophorectomy until they have completed childbearing to help them cope with their worries while waiting to undergo the procedure. Expanded informed consent protocols for prophylactic surgery that incorporate choices about treatment modalities for anxiety would allow women to make risk management decisions that take both their long-term physical and emotional well-being into account.

ACKNOWLEDGMENTS

We thank William Redd, Ph.D., Heiddis Valdimarsdottir, Ph.D., and Dana Bovjberg, Ph.D., for their feedback on the manuscript.

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JOURNAL OF WOMEN'S HEALTH & GENDER-BASED MEDICINE
Volume 10, Number 2, 2001
Mary Ann Liebert, Inc.

Guest Editorial

Anxiety and Uncertainty in Informed Decision Making

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IDENTIFYING RISK FACTORS for the development of disease has a long medical tradition.[1] Indeed, screening and intervention for those at risk are a major goal of our current medical system. Recent insight into the hereditary nature of some cancers and the advent of genetic testing have made risk assessment increasingly accurate.[2] In the case of ovarian cancer, however, new understanding of the molecular and genetic pathogenesis of the cancer has outstripped our ability to detect, prevent, and treat the disease. This leaves us in the difficult position of being able to predict risk for ovarian cancer but having little, if anything, to offer in terms of preventing it. Present recommendations for women at high risk for the development of ovarian cancer include prophylactic oophorectomy after childbearing has been completed.[3] Surgical menopause can have significant long-term sequelae, including osteoporosis, vasomotor instability, vaginal atrophy, and sexual dysfunction.[4] Although most of these consequences can be addressed with hormone replacement therapy (HRT), there are concerns about long-term use of estrogen.[5] Appropriate informed consent demands that women understand and can balance the pros and cons of such a surgical intervention with its long-term consequences. Although there are recent studies focusing on breast cancer, the effect of knowledge of personal risk of ovarian cancer on the anxiety level, quality of life, and medical decision making of patients has not been well evaluated.[6]

In the paper by Hurley et al. in this issue,[7] the authors examine the motivation of desire for prophylactic oophorectomy in a group of women with family histories of ovarian cancer. In 1997, the authors identified and subsequently interviewed a group of 94 women who had completed both the educational component of the Family Risk Assessment Program (FRAP) and 1 year of follow-up. A single telephone interview assessed anxiety reduction as a motivation for surgery in the context of perceived risk of cancer, family pedigree, and cancer-related intrusive thoughts. The researchers also examined the impact of desire for childbearing, fear of surgery, concerns about menopause and HRT, and beliefs about the risk reduction from surgery on these women's desire for oophorectomy. Stepwise regression showed that the desire to reduce anxiety and uncertainty was the strongest predictor of these women's current interest in surgery, and the sole variable predicting interest in future oophorectomy was the other benefits of surgery.

The importance of anxiety in women's desire for intervention to reduce cancer risk is not surprising. Interestingly, the degree of anxiety did not correlate with familial risk categories (putative hereditary, familial, or sporadic) in this group of women who had been educated regarding their risk. However, the authors report that anxiety, as well as current and past desire for surgery, was influenced by exposure to anxiety triggers, such as recent diagnoses of family members with cancer, the anniversaries of relatives' death, and the like. As the authors state, one of the limitations of the current study is its static nature; that is, it is based on an interview at one point in time. It certainly would be interesting to see a prospective study examining how anxiety and its impact on desire for surgery change over time. Of the 49 patients not considering surgery at the time of the study, 20 reported that they had considered it more strongly in the past. One way to interpret this information is to suggest that a waiting period be implemented between the time a woman is counseled about her risk of cancer

and her intervention options and the time those options are exercised.

Informed decision making about appropriate interventions is crucial. We will be confronted with questions about how anxiety and fear motivate medical decision making in a wider arena as other disease-associated genes are identified and as genetic testing becomes more prevalent. Interventions to manage anxiety might allow patients to assess their risk more accurately and give informed consent. Healthcare providers need to be cognizant of how anxiety and uncertainty play a role in their patients' decision making. The Hurley et al. paper is a good first step in addressing these concerns. Further prospective studies to evaluate the effect of anxiety-reduction interventions on decision making will be important.

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The Price of Vigilance: Monitoring, Beliefs about the Efficacy of Cancer Prevention, and Distress Among Women at Familial Risk for Ovarian Cancer

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Running Head: MONITORING AND PREVENTION BELIEFS

In order to take preventive action against a health threat, a person has to maintain sufficient awareness of the threat to decide on and carry out the action (Miller, 1980). For most individuals, the belief that one can effectively reduce one's risk of disease mitigates distress that may be aroused by thinking about the disease (Rippetoe & Rogers, 1987). However, for individuals who tend to focus on and amplify threat cues when confronted with a health threat (an attentional style known as monitoring; Miller, 1987; 1995), the attention to threat required by preventive behaviors may increase their vulnerability to distress about their risk.

Research shows that high monitors prototypically manifest greater distress than low monitors, but only in psychologically challenging situations that draw attention to the source of the threat, such as diagnositic procedures (Miller & Mangan, 1983; Miller, Roussi et al., 1994), positive cancer screening results (Wardle et al., 1993) and anticipation of genetic test results for heritable cancer risk (Tercyak et al., 2001). In such situations, monitors are more likely to have intrusive thoughts, ruminate about threat, have more difficulty controlling their cognitions,(Muris, Djongh, van Zuuren & ter Horst, 1994) and experience negative affect (Schwartz et al, 1995). When such distress in the present becomes overwhelming, the need for immediate relief may outweigh the possibility of avoiding harm in the future, and undermine the persistence needed to carry out a regimen of preventive action (Miller, Shoda, & Hurley, 1996).

From the model outlined above, one could predict that for monitors, a prevention behavior that needed to be carried out repeatedly, such as taking a pill every day or watching one's diet, would be particularly challenging, because such actions draw

attention to the threat on a daily basis. The more threat cues (in the form of thinking about prevention or engaging in prevention behaviors) one encounters, the more opportunities there are for anxiety about whether one will successfully ward off cancer. By contrast, one would expect monitors to be less distressed by an action to be taken only once, such as a surgical intervention. Indeed, monitors have been shown to prefer interventions administered by a physician or other expert (Miller, Brody & Summerton, 1988).

We investigated this threat activation model of the relations between monitoring, prevention beliefs, and distress among women at familial risk for ovarian cancer. Ovarian cancer, by virtue of having the highest rate of mortality among the gynecologic cancers (Greenlee et al., 2001), constitutes a severe threat sufficient to activate the characteristic vigilence of the monitoring style. There are neither distinctive early-warning symptoms nor sufficiently sensitive screening methods to reliably signal the presence of the disease until after it has spread (Hakama et al., 1996; Jacobs et al., 1999), a situation which would predispose monitors to scan for and amplify any sign of the disease. The fact that age of onset cannot be predicted with certainty would further serve to keep monitors chronically on alert.

Options for reducing ovarian cancer risk (both physician-recommended and those based on popular belief) include both ongoing, self-administered preventive behaviors and one-time surgical intervention, allowing us to test the differential effects of prevention strategies on distress among monitors. The two prevention methods recommended by physicians are prophylactic oophorectomy (removal of ovaries) and taking oral contraceptives, which have been estimated to reduce ovarian cancer risk by

50-98% (Struewing et al., 1995; Weber et al., 2000) **[MD please verify]** and 50% (Narod et al., 1998) respectively. Popular beliefs about cancer risk reduction include such means as diet, reducing stress and avoiding environmental toxins (Evans et al, 1985; Julien-Reynier et al., 1998), which are all carried out by an individual on a frequent or daily basis.

We hypothesized that high monitors would display higher levels of distress when they believed that there were a number of ongoing, self-administered prevention behaviors that they could perform to effectively reduce ovarian cancer risk. Conversely, we hypothesized that high monitors who believed that a one-time, physician administered method (prophylactic surgery) would effectively lower their risk of ovarian cancer would be less distressed than high monitors who believed that prophylactic surgery would not offer effective protection. In contrast to the high monitors, we predicted that levels of distress would be reduced for low monitors, and would not differ as a function of their beliefs about the efficacy of ongoing vs. one-time prevention options.

Methods

Overview and Background

The present study is part of a larger, ongoing clinical research effort being conducted with women who have a family history of breast and/or ovarian cancer through the Family Risk Assessment Program (FRAP) at Fox Chase Cancer Center, Philadelphia, PA. FRAP participants with at least one first-degree relative with ovarian cancer and who had been enrolled in FRAP for at least one year were notified by letter that a study was being conducted to obtain additional detail on attitudes and decision-making about ovarian cancer risk among FRAP participants. The letter stated that they would receive a telephone call inviting them to participate in a short, twenty-minute interview. Informed consent was obtained in writing and over the phone. Women who agree to participate were interviewed by phone by the first author or another graduate level clinical interviewer using the measures listed below. The present study combined a subset of baseline data previously collected from participants on entry into FRAP with data from the telephone interview.

Participants

Participants in the present study were women over the age of 25 with at least one first-degree relative (mother, sister, daughter) with ovarian cancer. As of January 1997, one hundred and sixty eligible women completed the educational component and one year follow-up in the FRAP program. Of these 160 women, one had moved out of the area and been terminated from the program, two had voluntarily opted out of the study, and one was deceased, leaving a total of 156 potential participants for the present study. Of the 111 women whom we were able to reach by phone before the end of the study, three declined to participate, for an acceptance rate of 97%. One woman was excluded due to cognitive difficulties. Thirteen of the women reached by phone had undergone prophylactic ovarian surgery and were excluded from the analyses because their risk for ovarian cancer was substantially lower than the rest of the sample.

Seventy-six women with complete sets of data were included in the present study. Participants had been enrolled in FRAP for an average of 3.7 years (s.d.=1.0, range 1.3 to 5.1) prior to being interviewed for this study. The mean age of participants was 39.16 years (s.d.=9.51, range 21-67). The majority of the participants were married (81.9%) and all were Caucasian. Three-quarters (76.3%) of the women had attended college or beyond.

Baseline Measures

The following information was drawn from the FRAP database. These measures were collected upon the participant's entry into FRAP at least one year before the present study.

Demographics. We assessed age, ethnicity, marital status, and education level.

Monitoring. The Miller Behavioral Style Scale (MBSS) consists of four scenarios describing threatening situations (being at the dentist, airplane trouble) and asks respondents to indicate which of eight coping responses they would perform, four of which reflect a monitoring, information-seeking style. The monitoring score is obtained by adding up the number of monitoring items endorsed across the four situations. Scores range from 0 to 16. The monitoring scale has been used in other populations at risk for cancer (Miller et al., 1994; Miller & Mangan, 1983; Lerman et al., 1994; Schwartz, Lerman, Miller et al., 1995; Wardle et al., 1992). Internal consistency of the monitoring scale in this study was .69, which is consistent with published reports (Miller, 1980, 1987, 1992; Miller, Leinbach et al., 1989). For this study, a median split was used to divide the sample into high and low monitors (high monitor: monitor scale total >= 11).

Telephone Interview.

Stress-related ideation: The Impact of Events Scale (IES; Horowitz et al., 1979) assesses threat-related ideation as a result of exposure to a stressor and has been extensively used with individuals at risk for cancer (Kash et al., 1992; Miller, Rodoletz et al., 1996; Schwartz et al., 1995). For the present study, participants were asked to respond to each item with respect to their familial risk for ovarian cancer. The measure has two subscales: a 7-item subscale assessing intrusive thoughts, images, dreams and distress at reminders of a specified stressor (intrusive ideation) and and an 8-item scale assessing efforts to avoid reminders of the stressor or put it out of one's mind (avoidance). Participants rate the frequency of symptoms on a weighted 4-point scale (0=not at all, 1=rarely, 3=sometimes, 5=often). Scores range from 0 to 35 for intrusive ideation and 0 to 40 for avoidance. Internal reliability of the intrusive ideation and

avoidance subscales in this sample was .87 and .78 respectively, consistent with published reports on individuals at familial risk for cancer (Schwartz et al., 1995).

Positive and negative affect. The 14-item brief version of the Profile of Mood States (POMS; Guadagnoli & Mor, 1989) was distilled from the original 65-item version (McNair, Lorr, & Droppleman, 1971/81). Items were selected for the brief version specifically because they had no somatic content, which makes this an appropriate measure to use with medical populations. The POMS-BRF consists of two scales of seven items each, one assessing negative affect and the other assessing positive affect. Items are rated by participants from 0=not at all to 4=extremely, yielding scale scores that range from 0 to 28. Internal consistency coefficients for the Positive and Negative affect subscales in this sample (.82 and .72, respectively) were consistent with published reports (Guadagnoli & Mor, 1989)

Efficacy of preventive health behaviors. Participants rated seven preventive health behaviors (e.g., reducing stress, taking oral contraceptives) on a five-point scale (1=not at all, 5=completely) for their effectiveness in preventing ovarian cancer. The scale demonstrated good internal consistency (Cronbach's alpha = .76). A total score was created by summing the number of behaviors that were rated as highly efficacious (4 or 5 on the five-point scale). Possible scores range from 0 (no behaviors rated very or extremely effective in preventing ovarian cancer) to 7 (all behaviors rated very or extremely effective in preventing ovarian cancer).

Efficacy of prophylactic oophorectomy. Belief in the efficacy of prophylactic oophorectomy was assessed by a single five-point item: "How effective is prophylactic surgery in preventing ovarian cancer?" (1=not at all, 5=completely).

Results

Preliminary Analyses

None of the participant characteristics (age, education, marital status, or length of time participating in the FRAP program) were related to any of the independent variables (monitoring, beliefs about efficacy of health behaviors, beliefs about efficacy of prophylactic surgery) or outcome variables (intrusive ideation, avoidance, negative affect or positive affect), and therefore were not included in further analyses.

Prevention beliefs

Approximately one-quarter of the sample (26.6%) believed that there were no effective ongoing prevention behaviors that would be very or extremely effective in reducing ovarian cancer risk. Twenty percent (20.2%) believed there was one ongoing action they could that would be very or extremely effective in reducing there risk. Almost one-third (31.9%) believed there were two or three ongoing behaviors that would be efficacious in reducing their risk and 21.3% believed there were four or more ongoing behaviors they could perform that would be very or extremely effective in reducing ovarian cancer risk. (See Table 1). As for one-time, physician-administered intervention (prophylactic oophorectomy), 40 believed that the procedure was "very" or "extremely" effective in reducing ovarian cancer risk and 36 believed that the procedure was only "moderately" or "somewhat" effective.

Effects of monitoring and perceived efficacy of preventive health behaviors on stress-related ideation and distress

We examined the effects of monitoring and perceived efficacy of preventive health behaviors using analysis of variance (ANOVA). We found a significant interaction for both intrusive ideation, $F(3,72) = 5.25$, $p<.03$ and avoidance, $F(3,72) = 5.27$, $p<.03$ (see Figure 1). Among high monitors, women who believed there were many efficacious preventive behaviors they could undertake to reduce ovarian cancer risk had higher intrusive ideation risk (9.54 vs. 1.33) and avoidance scores (10.27 vs. 2.25) than women who believed there were few or no efficacious preventive behaviors they could undertake to reduce ovarian cancer. By contrast, among low monitors, there were no differences in levels of intrusive ideation between women who believed there were many or few efficacious preventive behaviors they could undertake to reduce ovarian cancer risk. In other words, high monitors who believed that they had a lot of control over reducing their risk of ovarian cancer experienced more intrusive thoughts about their risk than high monitors who believed they had little control.

The same pattern of results held true for general distress (see Figure 2). There were interaction effects between monitoring and perceived efficacy of preventive health behaviors for both negative affect, $F(3,72) = 4.87$, $p<.03$, and positive affect, $F(3,72)=4.04$, $p<.05$, as measured by the POMS-BRF. High monitors who believed there were many efficacious preventive behaviors they could undertake to reduce ovarian cancer risk experienced more negative affect and less positive affect than high monitors who believed there were few or no efficacious preventive behaviors they could undertake to reduce ovarian cancer risk. Among low monitors, there were no differences in levels of negative affect or positive affect between women who believed there were many or few efficacious preventive behaviors they could undertake to reduce ovarian cancer risk

Effects of monitoring and belief in efficacy of prophylactic surgery on stress-related ideation and distress.

We examined the effects of monitoring and belief in efficacy of prophylactic surgery on stress-related ideation and general distress using analysis of variance (ANOVA). We found an interaction effect between monitoring and beliefs about the efficacy of prophylactic surgery for avoidant ideation, $F(3,72)=4.28$, $p<.04$ (Figure 3) and for negative affect, $F(3,72)=4.84$, $p<.03$ (Figure 4). High monitors who believed that the efficacy of prophylactic surgery in reducing ovarian cancer risk was moderate or less had higher levels of avoidance and negative affect than high monitors who believed that prophylactic surgery was very or extremely effective. Among low monitors, there were no differences in levels of avoidance or negative affect based on beliefs about the efficacy of prophylactic surgery. The same pattern was found for intrusive ideation (8.13 vs. 3.73), although the interaction term was not sigificant, $F(3,72) = 1.86$, $p<.18$ No main effects or interaction effects were found for monitoring and beliefs about the efficacy of prophylactic surgery for positive affect, $F(3,72)=.14$, n.s.

In sum, high monitors manifested distress when they believed that two or more preventive behaviors that required ongoing attention (e.g., diet, stress reduction, or taking oral contraceptives), were very or extremely effective in reducing cancer risk, but not when they believed that only one ongoing behavior or no ongoing behaviors would be effective in reducing risk. Conversely, high monitors reported higher levels of distress when they believed that a one-time, physician administered intervention (prophylactic surgery) would be at best only moderately effective in reducing risk. High monitors who believed that prophylactic surgery was very or extremely effective in reducing ovarian cancer risk reported low levels of distress. Low monitors had low levels of distress, irrespective of beliefs about either ongoing or one-time prevention strategies.

Discussion

The results of this study bore out our main hypotheses, that individuals at familial risk for ovarian cancer who characterized by the monitoring attentional style showed higher levels of distress when a) they believed that there were several, self-administered prevention behaviors (e.g. diet, stress-reduction) that were highly effective in reducing cancer risk, but that call attention to one's cancer risk on a daily or frequent basis; and b) when they believed that a single, one-time, physician-administered method would <u>not</u> be effective in reducing risk. By contrast, distress levels among low monitors were uniformly low, regardless of their beliefs about ovarian cancer prevention options.

Our results are consistent with previous research on high monitors, showing that they are not simply more globally distressed or neurotic than low monitors (Ludwick-Rosenthal & Neufeld, 1993; Miller, 1987; Steptoe & Vogele, 1992). Rather, high monitors are characterized by an attentional coping style that is stable, but is manifest

only when activated by specific cues about severe threats. In the case of prevention beliefs, health behaviors may trigger threat-related "loss" messages (e.g., "If I don't eat alot of fruits and vegetables, I'll die of cancer") that have been shown in high monitors to be associated with higher levels of intrusive ideation about cancer risk (Miller, Buzaglo et al., 1999). Left unchecked, intrusive ideation is associated with adverse outcomes such as depressed mood, denial, and avoidance of health behaviors such as screening (cites).

Based on the results of the present study, the threat activation model suggests a two-pronged clinical intervention strategy to reduce high monitors' vulnerability to distress triggered by their beliefs about cancer prevention. One approach is to de-emphasize the link between general health behaviors and threat through positive reframing (cite). For example, health practices such as eating a low-fat diet can be reconstrued as a "gain" by contributing to a positive outcome (e.g., promoting physical well-being), rather than as a "loss" (e.g., warding off a negative outcome). An alternative approach is to teach strategies for reducing distress that may be aroused in the course of carrying out a health behavior that reminds one of one's cancer risk. Such coping strategies include.....

The diversity of beliefs that we found regarding the efficacy of ovarian cancer prevention practices was striking and bears comment. At one end of the spectrum, a number appeared fatalistic, believing that little, if anything, can be done to prevent the disease. These individuals may be at risk for nonadherence to practices that may have health benefits in addition to cancer risk reduction (Steptoe et al., 1994). At the other extreme, some participants were very confident in the efficacy of cancer prevention practices, to an extent that outstrips available evidence. Eating a low-fat diet was rated as "very or extremely effective" in reducing ovarian cancer risk by half of the participants, whereas approximately one-quarter gave taking oral contraceptives the same ratings. Research to date actually shows the reverse: studies of oral contraceptives have consistantly shown to be associated a substantial reduction in ovarian cancer risk (Narod et al., 1998), whereas findings on dietary fat have been mixed (Kushi et al., 1999), with at most a modest impact on ovarian cancer risk (Parazzini et al., 2000). Similarly, stress reduction was also rated by large proportion of participants as being very or extremely effective in reducing ovarian cancer risk. The role of stress in cancer etiology is plausible via psychoneuroimmunological processes but available evidence suggests the effect may not be quite so strong as was endorsed in our sample (Grossarth-Maticek et al., 2000). Our findings underscore the importance of assessing subjective, popular beliefs in relation to health intentions and behavior.

There are certain limitations to the present study. This study was conducted with a relatively small sample of women attending a specialized clinic for familial breast and ovarian cancer risk. Results may not generalize to high risk individuals who choose not to attend such a clinic or to those who are at normal risk for cancer. In addition, we

assessed beliefs about the efficacy of prevention behaviors, but not the behaviors themselves. In another health context, high monitors have been shown to have more favorable attitudes towards preventive behaviors than low monitors, but were no more likely to carry them out (Muris, van Zuuren, & Kindt, 1994). Some may lack knowledge or self-efficacy to put their intentions to protect their health into action. Others may refrain from prevention behaviors in order to avoid encountering cues that would stimulate distress about the threat of cancer. In any case, individuals who are not engaging in practices that they believe to be effective may blame themselves for increasing their chances that cancer may strike, and may be distressed as a result. Past research on monitors show that they do, in fact, tend to blame themselves more for their medical problems (Miller, Roussi et al., 1994).

Further research in this area would help elucidate the processes underlying the associations we observed. A fundamental question is, whether distress in monitors holding a greater number of efficacious prevention beliefs is a function of number of threat-related cues encountered during the course of carrying out preventive actions? Or is the availability of instrumental control over cancer risk via preventive behaviors somehow threatening or overwhelming to monitors? Miller hypothesizes that monitors focus on threat, scan for threat cues, and gather as much information as possible even when confronted with uncontrollable threats in order to increase predictability of a threat (Miller, 1987). In support of this hypothesis, Zuuren and Wolfs (1991) found that monitoring was associated with predictability of a threatening situation, not its controllability. However, the very predictability that monitors seek may paradoxically short-circuit effective means to prevent the impending threat.

Our findings suggest that campaigns to promote cancer risk reduction behaviors among people at familial risk for cancer need to take into account variations in the subjective meaning of health-related beliefs and behaviors, or they may backfire among certain psychologically vulnerable individuals (cite studies matching intervention to style). By using the threat activation model, we were able to identify conditions under which monitors are susceptible to this type of undesirable reaction. Further understanding of cognitive-affective processes inherent in this model can lead to tailored interventions that minimize the price of vigilence in the face of the chronic level of threat posed by familial cancer risk, and empower individuals to take steps to protect their health in accordance with their preferred attentional style.

Acknowledgements

Preparation of this manuscript was supported in part by (kh grants, **sm grants, md grants- please fill in)**

This work is supported in part by the U.S. Army Medical Research and Materiel Command under Award Number DAMD 17-00-1-0355.

The views, opinions and/or findings contained in this document are those of theauthor(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

Acknowledgements: The authors thank Hayley Thompson, Ph.D. for statistical assistance

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Intrusive Ideation About Cancer Risk Before and After BRCA1/2 Mutation Testing

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Intrusive ideation (repetitive, unwanted thoughts) about one's cancer risk is a common and distressing psychological symptom among women with a family history of breast cancer. Negative outcomes associated with intrusive ideation about cancer risk include nonadherence to cancer screening, interest in prophylactic surgery in excess of actual risk, decreased quality of life, and depression. We examined levels of intrusive ideation among Ashkenazi Jewish women before they underwent counseling about genetic testing for BRCA1/2 mutations, and after they were counseled about their results.

55 women (age X=50.6) seeking genetic testing for breast/ovarian cancer risk completed pre-counseling and post-notification questionnaires. Regression analysis showed that post-notification intrusive ideation was predicted by baseline intrusive ideation($p<.0001$), past history of cancer($p<.01$), and mutation status($p<.05$). 30% of mutation carriers, 26.7% of those with inconclusive/negative results and 0% of true negatives had post-notification intrusive ideation scores in the clinical range (comparable to those seeking treatment for post-traumatic stress disorder). Approximately 1/3 of the sample reported an increase in intrusive ideation after receiving their results, regardless of mutation status. Affected women were more likely to report an increase in intrusive ideation after receiving inconclusive results than unaffected women($p<.05$). Finally, among a subset of the entire sample, although 100% were very/extremely satisfied with information received, and 77.8% found counseling very/extremely helpful in making medical decisions, only 22.3% felt that counseling fully met their need for emotional support.

Our data indicate an unmet need for psychological services among women undergoing testing for BRCA1/2 mutations, particularly affected women who receive inconclusive results. Addressing these needs will help women make effective use of the educational and decision-making gains achieved by genetic counseling to promote long-term emotional adjustment and adherence to risk-reduction behaviors.

COPING STRATEGIES AND INTEREST IN PROPHYLACTIC SURGERY

Karen Hurley, Ph.D., Heiddis Valdimarsdottir, Ph.D., Karen Brown, M.S., Lynn Stravinski, M.S., & Christine Eng, MD, Mt. Sinai School of Medicine

A reason frequently given by women with familial breast/ovarian cancer for undergoing genetic testing is to decide whether to undergo prophylactic mastectomy (PM) and/or oophorectomy (PO). Most women anticipate that if they test negative for a BRCA1/2 mutation, they would forego prophylactic surgery. We investigated levels of distress and coping strategies among women who indicated they would still consider prophylactic surgery even if they tested negative.

78 Ashkenazi Jewish women (mean age=49.31) presenting for BRCA1/2 testing filled out questionnaires prior to genetic counseling. Anticipated interest in PM despite a negative result was associated with intrusive ideation about cancer risk ($r=.42$, $p<.0001$), cancer worry that interfered with daily activities ($r=.30$, $p<.01$), and several palliative strategies for coping with cancer anxiety, including alcohol ($r=.42$, $p<.0001$), smoking ($r=.35$, $p<.003$), eating ($r=.25$, $p<.04$), and prescription anxiolytics ($r=.27$, $p<.02$). Similarly, anticipated interest in PO despite a negative result was marginally associated with intrusive ideation ($r=.23$, $p<.07$), worry about cancer that interfered with daily activities ($r=.33$, $p<.01$), and two palliative coping strategies: alcohol ($r=.33$, $p<.01$) and eating ($r=.22$, $p<.08$). Distraction and positive self-statements were not associated with anticipated interest in surgery.

Women presenting for genetic counseling who would consider prophylactic surgery in the event of a negative result appear to be at risk for high levels of cancer-related anxiety and for maladaptive strategies for coping with their anxiety. Awareness of this pattern would help genetic counselors identify patients who may benefit from psychological intervention to decrease distress, build coping skills, and promote appropriate medical decision-making.

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BIOGRAPHICAL SKETCH

Provide the following information for the key personnel in the order listed on Form Page 2.
Photocopy this page or follow this format for each person.

NAME	POSITION TITLE
Marc D. Schwartz	Assistant Professor of Oncology

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, and include postdoctoral training).*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	YEAR(s)	FIELD OF STUDY
SUNY at Albany, Albany, NY	B.A.	1986	Psychology
SUNY at Stony Brook, Stony Brook, NY	M.S.	1989	Clinical Psychology
SUNY at Stony Brook, Stony Brook, NY	Ph.D.	1992	Clinical Psychology
Memorial Sloan-Kettering Cancer Center	Post-Doc	1991-1993	Psycho-oncology

RESEARCH AND PROFESSIONAL EXPERIENCE: Concluding with present position, list, in chronological order, previous employment, experience, and honors. Include present membership on any Federal Government public advisory committee. List, in chronological order, the titles, all authors, and complete references to all publications during the past three years and to representative earlier publications pertinent to this application. If the list of publications in the last three years exceeds two pages, select the most pertinent publications. **DO NOT EXCEED TWO PAGES.**

PROFESSIONAL EXPERIENCE

1993-1995 **FOX CHASE CANCER CENTER**
Assistant Member, Division of Population Science

1995-present **GEORGETOWN UNIVERSITY MEDICAL CENTER**
Assistant Professor, Department of Psychiatry

1999-present **GEORGETOWN UNIVERSITY**
Assistant Professor of Oncology

1995-present **LOMBARDI CANCER CENTER**
Member, Cancer Control Program

2000-present **LOMBARDI CANCER CENTER**
Co-Director, Cancer Control Program

HONORS AND AWARDS

1989 Sigma Xi, The Scientific Research Society: Elected an Associate Member.
1991-1993 National Cancer Institute Post-doctoral Fellowship in Psycho-oncology.
1995 National Cancer Institute, Preventive Oncology Academic Career Award.

CURRENT RESEARCH GRANTS

Principal Investigator. Interactive Decision-Aid for BRCA1/2 Mutation Carriers. (RO1 CA82346), National Institute of Health/National Cancer Institute. $1,826,000, 1999-2004.

Principal Investigator. Decisions and Outcomes of BRCA1/2 Testing for Breast Patients (RO1 CA74861). National Institute of Health/National Cancer Institute, 1999-2001.

Co-Investigator Improving black men's knowledge of the prostate cancer screening dilemma. (K. Taylor, Principal Investigaotr) Centers for Disease Control, 1998-2001.

SELECTED PREVIOUS RESEARCH GRANTS

Principal Investigator. Preventive Oncology Academic Career Award (KO7 CA65597), National Institute of Health/National Cancer Institute. $350,000, 1995-2000.

Co-Principal Investigator. Comparing Models of Counseling for BRCA1/2 Testing (C. Hughes, Principal Investigator). National Institute of Health/National Institute of Human Genome Research, 1998-2001.

Principal Investigator. Psychological Distress and Adherence Among Women at Risk for Breast Cancer (R03 CA68182), National Institute of Health/National Cancer Institute. $50,000, 1995-1998.

Principal Investigator. Genetic Testing in Ashkenazi Jewish Women. Supplement to the Lombardi Cancer Center CCSG Grant, National Institute of Health/National Cancer Institute. $107,713, 1996-1998.

PUBLICATIONS

1. Jacobsen, P.B., Bovbjerg, D.H., **Schwartz, M.D.**, Andrykowski, M.A., Futterman, A.D., et al. (1993). Formation of food aversions in cancer patients receiving repeated infusions of chemotherapy. Beh Res and Therapy, 31, 739-748.
2. Jacobsen, P.B. & **Schwartz, M.D.** (1993). Food aversions during cancer chemotherapy: Incidence, etiology, and prevention. Oncology, 7, 139-143.
3. Lerman, C. & **Schwartz, M.** (1993). Adherence and psychological adjustment in women at high risk for breast cancer. Breast Cancer Research and Treatment, 28, 145-155.
4. Jacobsen, P.B., Bovbjerg, D.H., **Schwartz, M.D.**, Hudis, C.A., Gilewski, T.A., & Norton, L. (1995). Conditioned

emotional distress in women receiving chemotherapy for breast cancer. J of Consulting and Clinical Psychology, 63, 108-114.
5. **Schwartz, M.,** Lerman, C., Daly, M., Audrain, J., Masny, A., & Griffith, K. (1995). Utilization of ovarian cancer screening by women at increased risk. Cancer Epidemiology, Biomarkers, and Prevention, 4, 269-273.
6. **Schwartz, M.D.,** Lerman, C., Miller, S., Daly, M., & Masny, A. (1995). Coping disposition, perceptions of risk, and psychological distress among women at high risk for ovarian cancer. Health Psychology, 14, 232-235.
7. **Schwartz, M.D.,** Jacobsen, P.B., Bovbjerg, D.H., & Redd, W.H. (1996). The role of nausea in the development of conditioned taste aversions among cancer chemotherapy patients. Physiology and Behavior, 4/5, 659-663.
8. Lerman, C., **Schwartz, M.**, Miller, S., Daly, M., & Rimer, B. (1996). Psychological impact of breast cancer risk counseling:Interacting effects of coping style and education. Health Psychology, 15, 75-83.
9. Daly, M.B., Lerman, C.L., Ross, E., **Schwartz, M.D.,** Sands, C., Masny, A. (1996). Gail model breast cancer risk components are poor predictors of risk perception and preventive behavior. Breast Cancer Res & Treatment, 41, 59-70.
10. Lerman, C., **Schwartz, M.D.,** Lin, T.H., Narod, S., & Lynch, H.T. (1997). The influence of psychological distress on use of genetic testing for cancer risk. Journal of Consulting and Clinical Psychology, 65, 414-420.
11. Audrain, J., **Schwartz, M.D.,** Lerman, C., Hughes, C., Peshkin, B.N., & Biesecker, B. (1997). Psychological distress in women seeking genetic counseling for breast-ovarian cancer risk: The contributions of personality and appraisal. Annals of Behavioral Medicine, 19, 370-377.
12. **Schwartz, M.D.,** Lerman, C., Audrain, J., Cella, D., Garber, J., Rimer, B., Lin, T., et al., (1998). The impact of a brief problem-solving training intervention for relatives of recently diagnosed breast cancer patients. Ann Beh Med, 20, 7-12.
13. Valdimarsdottir, H.B., Bovbjerg, D.B., Brown, K., Jacobsen, P., **Schwartz, M.D.,** Bleiker, E., et al., (1999). Cancer-specific distress is related to women's decisions to undergo BRCA1 testing. Cancer Research, Therapy and Control, 8, 61-68.
14. **Schwartz, M.D.,** Rimer, B., Daly, M., Sands, C. & Lerman, C. (1999). A randomized trial of breast cancer risk counseling: The impact upon mammography utilization. American Journal of Public Health, 89, 924-926
15. **Schwartz, M.D.,** Taylor, K.L., Willard, K., Siegel, J., Lamdan, R., & Moran, K. (1999). Distress, personality, and mammography utilization among women with a family history of breast cancer. Health Psychology, 18, 327-332.
16. **Schwartz, M.D.,** Hughes, C., Roth, J., Main, D., Peshkin, B., Isaacs, C., Kavangh, C., & Lerman, C. (2000). Spiritual faith and genetic testing decisions among high risk breast cancer probands. Cancer Epi Bio & Prevention, 9, 381 -386.
17. **Schwartz, M.D.,** Lerman, C., Benkendorf, J., & Rothenberg, K. (2001). Attitudes toward the use of stored DNA samples for genetics research. American Journal of Medical Genetics, 98, 336-342.
18. **Schwartz, M.D.,** Lerman, C., & Rimer, B.K. (2001). Psychosocial interventions for women at increased risk for breast cancer. A. Baum and B. Anderson (Eds.), Psychosocial Interventions in Behavioral Medicine Washington DC:APA.
19. Tercyak, K.P., Lerman, C., Peshkin, B.N., Hughes, C., Main, D., Isaacs, C., **& Schwartz, M.D.** (2001). Effect of Coping Style and Test Result on Anxiety Among Women Participating in Genetic Counseling and Testing for Breast/Ovarian Cancer Risk. Health Psychology, 20, 217-222.
20. **Schwartz, M.D.,** Benkendorf, J., Lerman, C., Isaacs, C., Ryan, A., & Johnson, L. (in press). Educating Ashkenazi Jewish women about genetic testing for breast cancer susceptibility: A randomized trial. Cancer.
21. Isaacs, C., Peshkin, B., **Schwartz, M.D.**, Roth, J., Main, D., & Lerman, C. (in press). Breast and Ovarian Cancer Screening Among Participants in a Genetic Counseling Program. Breast Cancer Research and Treatment.
22. Hughes, C., Lerman, C., **Schwartz, M.D.**, Peshkin, B.N., Wenzel, L., Main, D., Corio, C., Tercyak, K., & Isaacs, C. (in press). All in the family: An evaluation of the process and context of family communication about BRCA1/2 genetic test results. American Journal of Medical Genetics.
23. Audrain, J., **Schwartz, M.D.**, Herrera, J., Goldman, P., & Bush, A. (in press). Determinants of Physical Activity in First-Degree Relatives of Breast Cancer Patients. Journal of Behavioral Medicine.
24. **Schwartz, M.D.,** Peshkin, B., Hughes, C., Main, D., Isaacs, C., & Lerman, C. (in press). The Impact of BRCA1/BRCA2 Mutation Testing on Psychological Distress in a Clinic-Based Sample. Journal of Clinical Oncology.
25. Cella, D., Hughes, C., Peterman, A., Chang, C., Peshkin, B.N., **Schwartz, M.D.,** Wenzel, L., Lemke, A., Marcus, A., & Lerman, C. (in press). A Brief Assessment of Concerns Associated With Genetic Testing: The Mulitdimensional Impact of Cancer Risk Outcomes (MICRO) Questionnaire. Health Psychology.
26. Taylor, K.L., Shelby, R.A., **Schwartz, M.D.**, Ackerman, J., LaSalle, V.H., Gelman, E.P, & McGuire, C. (submitted). Perception of cancer risk: The influence of considering personal risk in the context of the population's risk.
27. Peshkin, B.N., Isaacs, C., Hughes, C., Main, D., **Schwartz, M.D.**, Lerman, C. (submitted). Utilization of mammography following BRCA1/2 testing.
28. Taylor, K.L., Davis, J.L., Turner, R.O., Kerner, J.F., **Schwartz, M.D.**, Johnson, L., Leak, C. (submitted). Development of educational materials to improve knowledge of prostate cancer screening among African American men.