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Surveillance Behavior in Women Tested for BRCA 1/2  
Mutation

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FOREWORD

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## Introduction

This research project is aimed at examining psychological distress and processing of information associated with risk for breast cancer. To that end, we have been recruiting women with and without family histories of breast cancer and assessing their levels of self-reported distress and their cognitive processing of cancer-related information. Understanding the types and magnitude of women's distress and impaired processing of cancer-related information is critical because cancer-related distress has been associated with poorer compliance with screening behaviors, and impaired processing of cancer information may decrease women's knowledge and understanding of (and hence, compliance with) recommended screening guidelines. These concerns may be particularly salient among women who attend genetic counseling, as they receive complex, and oftentimes distressing information about their risk for the disease. The research project is one part of a larger training experience for the PI. Accomplishments in both the training and research components of the award to date are described below.

## Training Accomplishments

During the past year, the PI had the opportunity to participate in the diverse didactic training offerings of the Cancer Prevention and Control and Biobehavioral Medicine programs at Mount Sinai. Scheduled colloquia, as well as informal lunch meetings with Mount Sinai faculty from the Cancer Center, Departments of Oncology, Radiology, and Human Genetics were regularly attended. In addition, special seminars from invited guest lecturers were periodically scheduled, providing an opportunity to forge broader connections and establish networks of collaboration. For instance, this past year the PI had the opportunity to attend core course lectures from Drs. George Raptis and Roger Waltzman from the Department of Oncology who discussed epidemiology, diagnosis and curative treatment of breast cancer in its earliest stages, as well as palliative treatment during its advanced stages. Ms. Karen Brown, director of Cancer Genetic Counseling in the Department of Human Genetics discussed genetic risk for breast cancer and issues surrounding genetic counseling. Regular biostatistical core lectures by Dr. Gary Winkel both at the Cancer Center and at the CUNY graduate center provided ample opportunity for development of advanced biostatistical and data-analytic skills. Guest lecturers included Drs. Caryn Lerman, James Pennebaker, Karen Glans, Irving Kirsch, Herbert Spiegel, Terry Keane, and many other noted scholars of biobehavioral medicine. Finally, through weekly "work-in-progress" meetings, the PI was afforded the opportunity to present his ongoing research, providing a forum to further hone presentation and communication skills.

## Research Accomplishments

In this study, we aimed to assess distress and cognitive processing of cancer-related information among women in three groups 1) women with family histories of breast cancer who tested positive for BRCA1/2 mutations; 2) women with family histories of breast cancer who tested negative for BRCA1/2 mutations; and 3) women without family histories of breast cancer who have not undergone genetic testing. Our goal was to recruit 110 subjects by the time of this report. To date, 113 subjects have been recruited to the study: 76 without family histories of breast cancer and 37 with family histories of breast cancer. Mean age of the subjects is 37.5 (SD = 8.5, range = 24.4-55.5). Ethnic breakdown of the sample is as follows: 45% Caucasian, 33% Hispanic, 11% African American, 4% Asian, 4% Native American, 3% other ethnicities. We are experiencing difficulty recruiting women who test positive for BRCA1/2 mutations because of low base rates for the mutation in the general population. In the coming year, we anticipate broadening our recruitment efforts to include affiliate hospitals in the Mount Sinai system (e.g., Elmhurst, St. Barnabus) to increase our access to these women. In our initial efforts this past year, we recruited women with family histories of breast cancer who have not undergone genetic counseling. Comparing this group to a group of women without family histories of breast cancer has allowed us to explore the possibility that women with family histories of breast cancer have higher levels of persistent distress and impaired cancer-related information processing than women without such family histories. This endeavor has also allowed us to assess the sensitivity of our primary cognitive task, the cancer Stroop task, in during which subjects are asked to name the color of ink in which cancer-related words are printed on a sheet of paper. Designed to assess the degree to which the actual words distract the subject from the primary task (color naming), we indeed found that all women in this study of breast cancer took longer to color-name the cancer word list relative to other comparison word lists (i.e., heart disease, general threat, positive, and neutral color-words). To date, our findings indicate that in this sample, women with family histories reported higher levels of self-reported cancer specific intrusive thoughts and avoidance, and took significantly longer to color-name cancer words (i.e., increased vigilance to the cancer words distracted them from the primary task of color-naming) than did women without family histories of the disease. In further support of our hypothesis, we found a significant relation between objective risk for breast cancer (Gail Model, which includes factors such as age of menarche, age at first live birth, and number of children) and time to color name cancer words, such that those women with the highest levels of objective breast cancer risk took the longest time to color name the cancer words. These findings were significant ( $p < .005$ ), even after controlling for reading ability and education. Interestingly, Stroop reading times were not related to distress levels in these women, possibly suggesting that the Stroop may be sensitive to levels of

distress that are not being tapped by traditional self-report methods. Finally, consistent with the large body of literature on cognitive processing of anxiety-related stimuli, we found that memory for the cancer words in the Stroop task was poorer for women with family histories of breast cancer and for women with elevated objective risk. These findings suggest that women are initially exhibiting heightened vigilance toward putatively anxiety provoking materials (as evidenced by slower color naming times), but then demonstrate a subsequent cognitive avoidance of those same materials (as evidenced by poorer word recall). These findings are currently being prepared for submission as a presentation at the national meeting of the Society of Behavioral Medicine in Seattle next spring.

Another goal of this study is to assess how well the information that women receive during genetic counseling is processed, and the possibility that acute distress at the time of counseling may impact this information processing. To that end, the PI has spent much time in consultation with cancer genetic counselors at Mount Sinai and affiliate hospitals to learn about the process of information-giving during counseling. With the guidance of genetic counselors, we have developed a broad questionnaire that assesses the range of information provided during genetic counseling. At this time, in an ongoing validation study, the questionnaire is being completed by health care practitioners employed in a cancer setting, health care practitioners employed in other medical settings, genetic counselees, women with family histories of breast cancer who have not attended genetic counseling and women without family histories of breast cancer. To date, 30 subjects have been recruited (additional questionnaires are returned daily) and data analyses are awaiting further accrual. Ultimately, this validated questionnaire will allow us to assess the degree to which knowledge is increased by genetic counseling, and the degree to which psychological distress interferes with that process.

Finally, during this past year, the PI has had the opportunity to publish two original peer-reviewed articles on distress and breast cancer risk. In the first study, findings indicated that distress about breast cancer was related to poor compliance with recommended guidelines for monthly breast-self examination. These findings were published in the Journal of Behavioral Medicine (23, 277-92). In the second study, findings indicated that women with family histories of breast cancer who had the experience of caring for a mother who died of the disease were at particularly high risk of experiencing both cancer-specific distress and depressive symptoms, even years later. These results were published in the Annals of Behavioral Medicine (22, 53-9). The PI has also submitted a third paper in which he found that women with family histories of breast cancer are grossly overestimating their risks for developing breast cancer, and at the same time underestimating their risks for developing other diseases, especially heart disease, for which they are often at greater risk of developing. All in all, the PI's research, didactic and publication activities during the first year of this traineeship have been dedicated to better understanding distress associated with risk for breast cancer, and its potential impact on processing relevant information critical to women's decision-making about their health care.

### Key Research Accomplishments:

- Characterized distress levels in women with family histories of breast cancer
- Identified aberrant processing of cancer-related information in women at familial and objective risk for breast cancer
- Developed an instrument to assess knowledge gained during breast cancer genetic counseling (Knowledge Questionnaire)
- Initiated study to characterize reliability and validity of KQ

### Reportable Outcomes:

- Original peer-reviewed journal article: Erbllich, J., Bovbjerg, D., and Valdimarsdottir, H. (2000). *Psychological distress, health beliefs and frequency of breast self-examination*. Journal of Behavioral Medicine, 23, 277-292.
- Original peer-reviewed journal article: Erbllich, J., Bovbjerg, D., and Valdimarsdottir, H. (2000). *Looking forward and back: Distress among women at familial risk for breast cancer*. Annals of Behavioral Medicine, 22, 53-59.
- Submitted: Erbllich, J., Bovbjerg, D., Norman, C., Valdimarsdottir, H., and Montgomery, G. *It won't happen to me: Lower Perception of Heart Disease Risk among women with family histories of breast cancer*. Preventive Medicine.



## **Psychological Distress, Health Beliefs, and Frequency of Breast Self-Examination**

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*Although monthly breast self-examination (BSE) is recommended for early breast cancer detection, most women do not comply. Few studies have examined the impact of psychological distress on BSE frequency. Recent research suggests that it may be particularly important to examine the role of distress in the recently identified phenomenon of BSE overperformance (>1/month). One hundred thirty-five healthy women with and without family histories of breast cancer completed sociodemographic, health belief, general and cancer-specific psychological distress, and BSE frequency questionnaires. The central finding of the study was that BSE underperformance and overperformance had two distinct sets of predictors: health beliefs, specifically barriers against BSE and low confidence in BSE performance, were related to BSE underperformance, while higher levels of psychological distress, particularly cancer-specific intrusive thoughts, were related to BSE overperformance. Findings underscore the need to evaluate BSE under- and overperformance separately and to develop problem-specific interventions to increase compliance with monthly BSE.*

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**KEY WORDS:** psychological distress; health beliefs; breast self-examination; detection.

### **INTRODUCTION**

Breast cancer is currently one of the most frequent causes of mortality among women in the United States (American Cancer Society, 1999).

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Although curative treatment for breast cancer is increasingly successful, early detection and subsequent early intervention are critical in reducing mortality rates among women (American Cancer Society, 1999; Boring *et al.*, 1994). Of the three commonly employed methods of early breast cancer surveillance (clinical breast examination, mammography, and breast self-examination), only breast self-examination (BSE) allows women to perform a surveillance behavior independently and may often be the only screening method available for women without access to professional health care services. Although the efficacy of monthly BSE in reducing breast cancer mortality has not been supported in some studies (Holmberg *et al.*, 1997), it has been found to increase the likelihood of detecting early breast tumors in a number of other studies (Coleman, 1991; Hill *et al.*, 1988; Foster *et al.*, 1978). BSE, an inexpensive and convenient method of breast cancer surveillance, is currently the only recommended screening behavior for younger women (American Cancer Society, 1999). Indeed, monthly BSE is the recommendation of the American Cancer Society (1999) for all women over age 20 as part of routine breast care. Although the vast majority of breast cancers continue to be detected by women themselves (Brain *et al.*, 1999), research indicates that the most women perform BSE less frequently than the recommended monthly interval (Kash *et al.*, 1992; Houts *et al.*, 1991).

In addition to the problem of underperformance, there is growing awareness that a substantial subset of women may actually overperform BSE (e.g., Lauver and Angerame, 1990). Performing BSE more than once a month is thought to undermine its utility as a screening tool by decreasing women's sensitivity to developing abnormalities gradually, especially since frequent exams are likely not be performed as thoroughly (Epstein and Lerman, 1997; Epstein *et al.*, 1997). Indeed, the negative aspects of overperformance were already recognized at Haagensen (1952), whose seminal paper was the first to recommend that all women should perform monthly BSE.

A number of recent studies have aimed to identify sociodemographic factors that predict frequency of women's BSE performance, in the hopes of providing means for better targeting individual and communitywide intervention and education efforts. For example, some studies have suggested that African American women are more likely to underperform BSE than Caucasian women (Kaplan *et al.*, 1991), while one recent large-scale study concluded that African American women were more likely to overperform BSE (Epstein *et al.*, 1997). Similarly, there is mixed support for the impact of having a first degree relative with breast cancer on women's BSE frequency (Epstein *et al.*, 1997; Salazar and Carter, 1994; Alagna *et al.*, 1987). Indeed, the impact of objective risk based on the number of affected relatives (Claus *et al.*, 1996) or other known risk factors for breast cancer (e.g., age at menarche)

on BSE frequency has received little research attention. It is possible that women who have greater objective risk may be differentially motivated to perform BSE according to guidelines. Because African American women and women at familial risk for breast cancer have higher mortality rates from breast cancer (American Cancer Society, 1999), identifying predictors of BSE frequency in these women is particularly important. Other variables reported to be associated with BSE underperformance include age, education, and marital status (Duke *et al.*, 1994; Murray and McMillan, 1993). However, studies to date have examined largely sociodemographic correlates of BSE underperformance, with little attention given to the correlates of BSE overperformance [see Epstein *et al.* (1997) and Lerman *et al.* (1994) as exceptions].

In addition to studying the impact of sociodemographic variables on BSE frequency, recent investigations have explored variables derived from Rosenstock's (1966) Health Belief Model. The Health Belief Model and recent modifications (e.g., Champion, 1993) theorize that five factors relate to the performance of a surveillance behavior: perceived seriousness of the disease, perceived susceptibility to the disease, perceived benefits of engaging in the surveillance behavior (early detection, decreased mortality, etc.), perceived barriers to engaging in the behavior (time consuming, embarrassing, etc.), and confidence in correctly performing the surveillance behavior to maximize its utility.

Numerous studies of health belief variables have found that greater perceived barriers to BSE predicted underperformance (e.g., Barron *et al.*, 1997; Champion, 1988); fewer perceived benefits have been more equivocally related to BSE underperformance. Lower confidence in one's ability to perform BSE predicted underperformance in a number of studies (Katz *et al.*, 1995; Duke *et al.*, 1994; Fletcher *et al.*, 1989; Ronis and Kaiser, 1989; Jacob *et al.*, 1984). Lower perceived susceptibility also predicted BSE underperformance in several studies (e.g., McCaul *et al.*, 1996; Salazar and Carter, 1994). Finally, lower perceived seriousness predicted BSE underperformance in two studies (Champion, 1993, 1988). To our knowledge, no previous studies have examined the possible roles of health belief variables in predicting BSE overperformance.

Although studies based on the Health Belief Model have sometimes assessed certain types of psychological distress related to screening behaviors (such as fear of finding a lump—a health belief “Barrier”), formal assessments of general and cancer-specific distress and their relations to BSE frequency are rare in the literature. The potential importance of psychological factors is suggested by Leventhal's Dual Process Model (Leventhal and Cameron, 1987), which posits that fear and anxiety may play a role in influencing health and screening behaviors. One study found

that general psychological distress measured by the Brief Symptom Inventory (BSI) (Derogatis and Spencer, 1982) correlated negatively with BSE frequency (Lerman *et al.*, 1994). Kash *et al.* (1992) reported that general anxiety was negatively related to BSE frequency, but it is unclear how they measured BSE frequency. Other studies have found that cancer-specific distress, such as intrusive thoughts about breast cancer, correlated positively with BSE adherence (Benedict *et al.*, 1997; McCaul *et al.*, 1996), but BSE overperformance was not examined. Epstein *et al.* (1997) and Brain *et al.* (1999) found that high levels of cancer-specific distress correlated with BSE overperformance among women with family histories of breast cancer. Lerman and colleagues (1994), the first to assess concurrently both BSE overperformance and BSE underperformance, found that psychological distress measured by a global score on the BSI related to BSE underperformance and that cancer-specific distress related to BSE overperformance among women with family histories of breast cancer. The literature thus remains equivocal in terms of the role of psychological distress in predicting BSE frequency, especially BSE overperformance, and replication remains scarce. Additionally, the predictive value of psychological distress beyond what can be attributed to classic health belief variables has yet to be examined.

To our knowledge, the study reported here is the first to examine concurrently psychological distress, as well as health beliefs, family history, and sociodemographic variables, as possible predictors of BSE underperformance and overperformance within a single study. These factors were assessed contemporaneously to facilitate analysis of the unique contributions of psychological distress to the prediction of BSE frequency, allowing a more encompassing picture of the factors associated with women's compliance to the recommended guideline of monthly BSE. In light of recent findings that women with family histories of breast cancer and African American women may be less likely to comply with recommended guidelines for monthly BSE, we targeted recruitment to ensure adequate representation of these groups in the study. Based on the previous literature, we hypothesized that psychological distress, health beliefs, breast cancer risk factors, and sociodemographic variables would each predict BSE frequency when considered individually. To provide the first critical test of the impact of psychological distress above and beyond other predictors, we examined the possibility that psychological distress would predict BSE frequency even after accounting for factors in the Health Belief Model. Based on the reports by Epstein *et al.* (1997) and Brain *et al.* (1999), we hypothesized that high cancer-specific distress would predict BSE overperformance and that African American women would be overrepresented in the subset of women who overperformed BSE.

## METHOD

### Subjects

One hundred forty-two women with ( $n = 54$ ) and without ( $n = 88$ ) first-degree relatives with breast cancer participated in the study. Subjects were recruited by advertisements placed in three medical centers in New York City requesting participants for a study of family history and breast cancer. To accrue sufficient numbers of women with family histories of breast cancer and African American women, our recruitment advertisement especially encouraged these women to attend. Fewer than 10% of women refused to participate once contacted. Women were eligible to participate if they were healthy by self-report and had no personal history of cancer at the time of the assessment. Women reporting taking any prescription medications or suffering from chronic illnesses (e.g., diabetes) were excluded from the study. Additionally, women with family histories of breast cancer were excluded if their relative had been in active treatment for breast cancer within the previous 6 months. We made these exclusions to decrease the likelihood that women were currently dealing with other major health-related issues that would potentially impact attitudes toward breast cancer screening. Seven subjects were excluded because of missing data, yielding a final sample of 135 women. Mean age of the sample was 41.6 years ( $SD = 10.1$  years). Over a third of the sample had family histories of breast cancer, two-thirds were minority participants, about half had completed college, and a third were currently married (see Table I).

### Measures

Subjects completed questionnaires assessing demographics and family history of cancer. They also reported possible risk factors for breast cancer, including age at menarche, age at first live birth, and number of children

**Table I.** Subject Characteristics: Demographics and Risk Factors

Mean age (years)	41.6 ( $SD = 10.1$ )
Education (% completed college)	53
Income (% earning above \$40,000)	39
Marital status (% married)	33
Ethnicity (% Caucasian)	30
Familial risk (% with a FH to breast cancer)	38
Objective risk (% with Claus score >11)	30
Mean age at menarche	12.4 ( $SD = 1.9$ )
Mean age at first live birth	23.4 ( $SD = 5.6$ )
Mean number of children	2.7 ( $SD = 1.7$ )

(Gail *et al.*, 1989). Objective risk estimates (>11% lifetime risk) were calculated using the Claus *et al.* (1996) formulation of familial risk based on pedigree analyses. In addition, subjects completed face valid items assessing health beliefs, reported to be predictors of screening behaviors in other studies (Rakowski *et al.*, 1992; Lerman *et al.*, 1990; Rimer *et al.*, 1989, 1991). Perceived seriousness was assessed by having subjects rate "How serious of a disease do you think breast cancer is?" on a scale from 0 ("not serious at all") to 100 ("as serious as can be") and perceived susceptibility was assessed by having subjects rate "How likely do you think you are to develop breast cancer in your lifetime?" on a scale of 0 ("not at all likely") to 100 ("extremely likely"). These face valid measures have been used previously in studies from our own laboratory (e.g., Zakowski *et al.*, 1997, Valdimarsdottir *et al.*, 1995) and by others (e.g., Durfy *et al.*, 1999) and have demonstrated stability over time [test-retest reliability = .85 (Zakowski *et al.*, 1997)] and criterion validity (Zakowski *et al.*, 1997; Valdimarsdottir *et al.*, 1995). They also rated the degree to which they agreed with the benefits of BSE performance ("helps detect breast cancer early," "may relieve anxiety," "gives a feeling of control over health," "may benefit the whole family," etc.) and the barriers to BSE performance ("embarrassing," "time consuming," "unnecessary unless there are symptoms," "nothing can be done anyway at that point," etc.) on an 18-item Likert-type scale of 1 (strongly disagree) to 5 (strongly agree) based on benefits and barriers reported in a number of studies (Rakowski *et al.*, 1992; Lerman *et al.*, 1990; Rimer *et al.*, 1989, 1991). Subjects also reported on a Likert-type scale of 1 to 5 how confident they were in their ability to adequately perform BSE. Reliability of health belief measures in this sample ranged from .66 to .84, comparable to coefficients reported in other studies of health beliefs (Champion, 1988).

General psychological distress was measured using the Brief Symptom Inventory (BSI) (Derogatis and Spencer, 1982). The reliability of this measure has been demonstrated by internal consistency [Cronbach's  $\alpha = .80-.90$  (Derogatis and Spencer, 1982)] and had a reliability coefficient of .95 in the present sample. As an additional measure of distress, mood disturbance on the day of assessment was measured using the short version of the Profile of Mood States (POMS-SV) (Shacham, 1983; DiLorenzo *et al.*, 1999). Reliability of the POMS has been reported to be .73-.97 by the authors and was .93 in the present sample. To simplify analyses, only total scores on the BSI and POMS-SV were used. The BSI total score was calculated by summing the responses to the 53 items (Likert from 0 to 4) and dividing by 53, yielding a score range of 0 to 4. Higher numbers reflect greater general distress. The POMS-SV was scored by summing responses (Likert 0 to 4) of negative affect items (e.g., hopeless, anxious) and subtracting responses to positive affect items (e.g., carefree, cheerful), yielding a score range of -24 to 124. Similar to the BSI, higher scores reflect greater mood disturbance. Cancer-specific

distress was measured using the Impact of Events Scale (IES) (Horowitz *et al.*, 1979), which is comprised of two subscales: intrusive thoughts and avoidance. "Breast Cancer" served as the "event" on the IES. Internal consistency of the IES has been reported as .86-.89 (Horowitz *et al.*, 1979) and was .93 in the present sample. The Intrusive Thoughts subscale consists of seven Likert-type items (0 to 5) assessing the frequency of thoughts about breast cancer (e.g., thought about it when I didn't mean to), yielding a score range from 0 to 35. The Avoidance subscale consists of eight Likert-type items (0 to 5) assessing the frequency of avoidant thoughts about breast cancer (e.g., I tried not to think about it), yielding a score range from 0 to 40. On both subscales, higher scores reflect more frequent thoughts. Finally, as additional measures of "cancer screening-specific" distress, subjects rated the degree to which they experienced distress when thinking about BSE and when performing BSE. They were instructed to mark a 100-mm line anchored by "not at all upset" on the left to "as upset as I could be" on the right. To minimize retrospective bias, cancer-screening-specific distress items were completed only by subjects who performed ( $n = 92$ ) or thought about performing ( $n = 96$ ) BSE within the previous month.

To assess compliance with the recommended guideline of monthly BSE (American Cancer Society, 1999), we asked subjects to indicate how frequently they performed BSE over the past 12 months, according to the following categories: never, once per year, once every 6 months, once every 2 months, once per month, or more often than once per month. Consistent with recent studies (Salazar, 1994; Tang *et al.*, 1999), we categorized appropriate performance as once per month or once per 2 months (to allow for regular BSE performers who may occasionally miss some performances), BSE underperformance as less often than every other month, and BSE overperformance as more often than monthly (Lerman *et al.*, 1994).

### Procedures

Subjects provided informed consent prior to participation. Questionnaires were completed in the presence of an investigator who was available to clarify any items, though they were permitted to complete the demographic portion of the questionnaire at home and return it in a prepaid mailer. Subjects were offered \$20 plus the cost of public transportation to and from the study visit.

### Data Analysis

Following the methodology of Lerman *et al.* (1994), our primary approach was to compare subgroups of women who (a) underperformed, (b)



overperformed, or (c) met performance guidelines for regular BSE. Preliminary analyses evaluated each continuous predictor variable for normality, and variables which failed to meet criteria (seriousness, susceptibility, confidence, and distress variables) were dichotomized. To address concerns of nonnormality, in line with methodology of previous studies (Lerman *et al.*, 1994), perceived seriousness (median = 100,  $M = 92.7$ ,  $SD = 15.2$ ) and susceptibility (median = 50,  $M = 38.6$ ,  $SD = 30.0$ ) were dichotomized at the median. As indicated, half of the women perceived breast cancer as "extremely serious," and half of the women rated their susceptibility to developing breast cancer in their lifetimes as "50" or greater. To facilitate chi-square and polychotomous logistic regression analyses, we generated a dichotomous "confident/not confident" variable from the original BSE confidence item. BSI Global Severity Index (median = 0.32,  $M = 0.44$ ,  $SD = 0.43$ ), POMS (median = 24,  $M = 30.8$ ,  $SD = 23.1$ ), IES Intrusive thoughts (median = 2,  $M = 4.1$ ,  $SD = 6.5$ ), IES Avoidance (median = 2,  $M = 5.7$ ,  $SD = 8.8$ ), Distress Thinking of BSE (median = 5,  $M = 14.3$ ,  $SD = 23.0$ ), and Distress Performing BSE scores (median = 5,  $M = 16.5$ ,  $SD = 23.6$ ) were all dichotomized at the median, as well. The distress variables were all positively skewed, with many subjects reporting no distress. Bivariate analyses on categorical and dichotomous variables were conducted using the chi-square statistic. Continuous variables (current age, age at menarche, age at first live birth, number of children, perceived benefits, and perceived barriers) were analyzed using the one-way ANOVA technique with Duncan's (1975) pairwise comparison test. Unique contributions of the psychological variables were assessed with a polychotomous hierarchical multiple logistic regression analysis (used when the dependent variable has more than two levels, as in the present study assessing under-, regular, and overperformance of BSE) (Hosmer and Lemeshow, 1989). All statistical tests were two-tailed.

## RESULTS

Findings indicated that 36% ( $n = 49$ ) of the women met recommended guidelines for regular BSE, while an almost-equal number of women underperformed BSE (36%,  $n = 48$ ), and 28% ( $n = 38$ ) of the women overperformed BSE. Bivariate analyses of the relations between BSE frequency and demographics, health beliefs, and psychological distress are presented below.

### Demographics

As indicated in Table II, when considered individually, age [ $F(2, 133) = 5.28$ ,  $p < .05$ ], level of education [ $\chi^2(2) = 9.21$ ,  $p < .05$ ], and ethnicity [ $\chi^2(2) = 6.57$ ,  $p < .05$ ] were related to BSE frequency. *Post hoc* analysis of

Table II. Bivariate Associations Between Subject Characteristics and BSE Frequency

Variable	Under performance (n = 48)	Regular performance (n = 49)	Over performance (n = 38)
Mean age (years)	38.9 <sup>a</sup> (SD = 9.3)	42.2 (SD = 11.3)	44.2 <sup>a</sup> (SD = 8.9)
Education (% completed college)	65 <sup>a</sup>	57 <sup>b</sup>	32 <sup>a,b</sup>
Income (% above \$40,000)	50 <sup>c</sup>	30 <sup>c</sup>	35
Ethnicity (% African American)	44 <sup>a</sup>	55 <sup>c</sup>	74 <sup>a,c</sup>
Family history (% with a FH of breast cancer)	38	31	47
Objective risk (% with Claus score >11)	31	26	32
Mean age at menarche	12.2 (SD = 1.9)	12.5 (SD = 1.9)	12.6 (SD = 1.8)
Mean age at first live birth	24.4 (SD = 5.1)	23.0 (SD = 5.8)	22.7 (SD = 5.9)
Mean number of children	3.0 (SD = 2.0)	2.2 (SD = 1.6)	2.8 (SD = 1.2)

Note. <sup>a,b</sup>Values in each row with matching superscripts differ significantly, at  $p < .05$ . <sup>c</sup>Values in each row with matching superscripts differ at  $p < .10$ .

age indicated that the mean age of Underperformers (38.9; SD = 9.3) did not differ from that of Regular Performers (42.2 years; SD = 11.3 years), but did differ ( $p < .05$ ) from that of Overperformers (44.2 years; SD = 8.9 years). Additionally, *post hoc* cell comparisons indicated that significantly more Underperformers and Regular Performers completed college than did Overperformers ( $p < .05$ ). Consistent with earlier research, *post hoc* cell comparisons indicated that significantly more Overperformers were African American than Underperformers ( $p < .05$ ). Marital status was not related to BSE frequency in this sample. Having a family history of breast cancer in one or more first-degree relatives, having an objective (Claus *et al.*, 1996) lifetime risk greater than the base rate (11%), and having other objective risk factors for breast cancer (Gail *et al.*, 1989) were also not related to BSE frequency. These findings are consistent with a number of recent studies failing to support the hypothesis of risk-related differences in BSE behavior (Alagna *et al.*, 1987).

### Health Beliefs

As indicated in Table III, perceived barriers [ $F(2,133) = 9.12$ ,  $p < .05$ ] and confidence in BSE performance [ $\chi^2(2) = 7.63$ ,  $p < .05$ ] were related to BSE frequency. Underperformers were less likely to report being confident in BSE performance and scored higher on the Perceived Barriers scale than Regular Performers and Overperformers ( $p < .05$ ). Overperformers did not differ from Regular Performers on any of the health belief variables. Interestingly, perceived risk and perceived benefits were not related to BSE frequency.

**Table III.** Bivariate Associations Between Health Belief Variables and BSE Frequency

Variable	Under performance (n = 48)	Regular performance (n = 49)	Over performance (n = 38)
Perceived seriousness (% above median)	56 <sup>c,d</sup>	73 <sup>c</sup>	79 <sup>d</sup>
Perceived risk (% above median)	44	57	57
Mean perceived benefits	3.9 (SD = 0.6)	4.1 (SD = 0.8)	4.0 (SD = 0.8)
Mean perceived barriers	1.9 <sup>a,b</sup> (SD = 0.7)	1.4 <sup>a</sup> (SD = 0.6)	1.4 <sup>b</sup> (SD = 0.5)
BSE confidence (% reporting confidence)	33 <sup>a,b</sup>	59 <sup>a</sup>	57 <sup>b</sup>

Note. <sup>a,b</sup>Values in each row with matching superscripts differ significantly, at  $p < .05$ .  
<sup>c,d</sup>Values in each row with matching superscripts differ at  $p < .10$ .

### Psychological Variables

As indicated in Table IV, breast cancer-specific intrusive thoughts [ $\chi^2(2) = 12.66, p < .05$ ] and avoidance [ $\chi^2(2) = 11.49, p < .05$ ] were related to BSE overperformance. *Post hoc* comparisons indicated that 76% percent of Overperformers had high intrusive thoughts of breast cancer, significantly more than either Regular Performers or Underperformers. Similarly, 76% of Overperformers had high avoidance, significantly more than Regular Performers or Underperformers. BSE distress, general distress (BSI Global

**Table IV.** Bivariate Associations Between Psychologic Distress and BSE Frequency

Variable	Under performance (n = 48)	Regular performance (n = 49)	Over performance (n = 38)
BSI Global Severity Index (GSI) (% scoring above median)	50	52	60
POMS Acute Mood Disturbance (% above median)	37	49	50
Intrusive breast cancer thoughts (% above median)	42 <sup>a</sup>	46 <sup>b</sup>	76 <sup>a,b</sup>
Avoidance (% above median)	44 <sup>a</sup>	44 <sup>b</sup>	76 <sup>a,b</sup>
Emotional upset during BSE (% above median) <sup>a</sup>	25 <sup>c</sup>	34 <sup>d</sup>	53 <sup>c,d</sup>
Emotional upset thinking of BSE (% above median)	52	39	51

Note. <sup>a,b</sup>Values in each row with matching superscripts differ significantly, at  $p < .05$ .  
<sup>c,d</sup>Values in each row with matching superscripts differ at  $p < .10$ .

<sup>a</sup>Includes only subjects who performed BSE in the past month.

Severity Index), and acute mood disturbance (POMS-SV) were not related to BSE frequency at the .05 level of significance.

### Hierarchical Model

To determine the unique contributions of the psychological variables to BSE frequency, a polychotomous hierarchical multiple logistic regression was performed, using BSE frequency as the outcome variable. Our strategy was to enter demographic variables first, then health belief variables, to identify the contribution of health belief factors after accounting for demographics, and finally, to enter psychological variables, to identify their unique contribution to BSE behavior after accounting for both demographics and health beliefs (Table V). To take a conservative approach, variables that reached even a marginally significant level ( $p < .10$ ) in the bivariate analysis were entered into the regression. When demographic variables (age, education, income, and ethnicity) were entered in the first block, education significantly predicted BSE ( $\chi^2 = 7.7$ ,  $p < .005$ ). The bivariate odds ratio indicated that Overperformers were less likely to be highly educated than Regular Performers (OR = .36; 95% CI = .15, .89). Health belief variables that were significant in the bivariate analyses (barriers, confidence) were entered in the second block. Results indicated that barriers and confidence were significantly related to BSE even after accounting for education ( $\chi^2$  change = 17.2,  $p < .005$ ). The bivariate odds ratios indicated that Underperformers were less likely to be

**Table V.** Hierarchical Logistic Regression Predicting Breast-Self Examination Frequency

Significant variable	$\chi^2$ improvement	Bivariate odds ratio (95% CI)
Step 1—Demographics	7.7	Over vs. Regular
Education		.36** (.15, .89)
Step 2—Health Belief Model	17.2	Under vs. Regular
Perceived barriers		3.57** (1.61, 7.70)
BSE confidence		.34** (.15, .79)
Step 3a—Psychologic distress (all subjects)	7.2	Over vs. Regular
Intrusive breast cancer thoughts		3.81** (1.49, 9.74)
Step 3b—Psychologic distress (subjects who performed BSE in the past month)	13.9	Over vs. Regular
Emotional upset during BSE		2.16* (.86, 5.40)
Intrusive breast cancer thoughts		4.35** (1.55, 12.16)

Note. \*  $p < .10$ . \*\*  $p < .005$ .

confident about BSE (OR = .34; 95% CI = .15, .79), and reported higher Barriers (OR = 3.81; 95% CI = 1.61, 7.70), than Regular Performers. In the final block, the significant psychological variables (intrusive thoughts, avoidance, and emotional upset when performing BSE) were entered. Results indicated that the intrusive breast cancer thoughts and emotional upset during BSE continued to be significantly related to BSE frequency even after accounting for the demographic and health belief variables ( $\chi^2$  change = 13.9,  $p < .005$ ). The bivariate odds ratios indicated that Overperformers were significantly more likely to report Intrusive thoughts about breast cancer (OR = 4.35; 95% CI = 1.55, 12.16) than Regular performers.

## DISCUSSION

The present study examined the impact of sociodemographics, health beliefs, and psychological distress on adherence to regular BSE. To our knowledge, this is the first study to assess the unique contribution of psychological distress as a predictor of BSE frequency over and above contributions from other variables. In addition, this is the first study to examine contemporaneously these variables' impact on BSE underperformance and overperformance in a sample including women both with and without family histories of breast cancer. Findings indicated that education, barriers, confidence, and cancer-specific distress made significant contributions to variance in BSE frequency and that cancer-specific distress was related to BSE even after accounting for the contributions of the other variables. Distress was related only to overperformance, while the health belief variables were related only to underperformance.

Our finding that 28% of women were Overperformers is consistent with Lerman *et al.* (1994), who found that 15–36% of their samples of women with family histories of breast cancer performed BSE more frequently than once a month. Indeed, Epstein *et al.* (1997) reported that 8% of women performed BSE as frequently as once a day. Future studies investigating BSE frequency within the subset of overperforming women may be useful in determining whether or not women who perform BSE daily differ from those who overperform less markedly.

The present finding that women who overperform BSE differ from women who regularly perform BSE also suggests that future studies should not combine these two groups and simply compare them to women who underperform BSE. For example, in the present study, if we were to have compared the Underperformers to the combined group of Regular Performers and Overperformers, we might have erroneously concluded that women who underperformed BSE were characterized by lower levels of cancer-specific

intrusive thoughts, when in reality, the percentage of Underperformers and Regular Performers who exhibited intrusive thoughts were almost-identical (Table IV). Hence, examining Overperformers separately from Regular Performers not only yields valuable information about BSE overperformance but also allows for more accurate conclusions about characteristics of women who underperform BSE.

In this sample, women with family histories of breast cancer were no more likely than others to perform BSE regularly. It should be noted that in the present study, women were recruited from medical centers to a study about breast cancer. One might argue that such women may well be more aware of the need for breast cancer screening than the general population, yet, surprisingly, many of the women in our sample were noncompliant with regular BSE. The possibility, thus, exists that noncompliance may be even greater in the general population. Because women with family histories are at greater risk to develop breast cancer, research and intervention efforts should focus on increasing compliance to screening guidelines in this population. The present findings suggest that such intervention efforts, now an active area of research, might most profitably be focused on removing perceived barriers, increasing BSE confidence, and alleviating cancer-specific distress.

It must be emphasized that the present findings are correlational and, thus, cannot formally demonstrate that relations between cancer-specific distress and BSE overperformance are causal in nature. It is also possible that BSE overperformance generates the cancer-specific distress observed in this sample. A third possibility is that BSE is both distressing in itself and maintained by women's distress about their risk. A vicious cycle may develop in which BSE performance causes cancer-specific distress, which in turn stimulates additional examinations, and so forth. Indeed, since the inception of BSE as a screening method, clinicians have been wary of the "cancerphobia" that may be related to overperformance (Haagensen, 1952). Also, frequency is only one important factor in effective BSE; proficiency in the techniques is equally critical. Intervention efforts should ensure not only that women are performing regular BSE, but that they are performing it correctly. Finally, as is the case in the preponderance of studies, we relied on women's self-report of BSE frequency, which could be responsive to demand characteristics; the relation between self-reports and actual frequency was not ascertained.

In sum, the present study is consistent with an emerging body of evidence suggesting that BSE overperformance may be a prevalent problem. Our study indicated that BSE overperformance has fundamentally different predictors than BSE underperformance. These findings suggest that Overperformers comprise a distinct group of women and should not be simply combined with Regular Performance in comparison to Underperformers, as

has been done in previous studies. Such oversimplification may lead to misleading and erroneous conclusions about predictors of underperformance as well as failure to characterize the potentially unique profile of women who overperform BSE.

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## **The Relative Efficacy of Three Cognitive-Behavioral Treatment Approaches to Temporomandibular Disorders**

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*The purpose of this study was to evaluate the relative efficacy of different biopsychosocial treatment conditions on patients with chronic temporomandibular disorder. Ninety-four patients with chronic temporomandibular disorder were assigned to either a biofeedback treatment group, a cognitive-behavioral skills training (CBST) treatment group, a combined (combination of biofeedback/CBST) treatment group, or a no-treatment control group. Pain scores were analyzed pretreatment and posttreatment to determine group and within-subjects treatment effects. Results demonstrated that, in terms of a self-reported pain score, all three treatment groups had significantly decreased pain scores from pretreatment to posttreatment, while the no-treatment group did not. Moreover, patients in the biofeedback group were the most significantly improved compared to the no-treatment group. Finally, participants in the three treatment groups displayed significant improvement in mood states.*

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**KEY WORDS:** temporomandibular disorder; biopsychosocial perspective; cognitive-behavioral skills training; biofeedback; RDC/TMD diagnosis.

### **INTRODUCTION**

Temporomandibular disorders (TMD) can be defined as a heterogeneous collection of disorders that are marked by orofacial pain, masticatory dysfunction, or both. Dworkin and LeResche (1992) developed the Research

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# LOOKING FORWARD AND BACK: DISTRESS AMONG WOMEN AT FAMILIAL RISK FOR BREAST CANCER<sup>1,2,3</sup>

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## ABSTRACT

Healthy women with family histories of breast cancer in a first-degree relative (FH+) have been reported to exhibit higher levels of breast cancer-related distress than women without family histories of breast cancer (FH-). Recent data suggest that this may be particularly true for women who had a parent die of cancer. In line with theories emphasizing the psychological impacts of past stressors and concerns for the future, the present study examined the hypotheses that past cancer stressors (i.e. maternal breast cancer caregiving and death, "Looking Back") and perceptions of one's own heightened future risk for developing the disease ("Looking Forward") would predict current levels of distress. One hundred forty-eight healthy women (57 FH+, 91 FH-) recruited from large medical centers in the New York City area completed measures of breast cancer-related distress, general psychological distress, and items assessing whether or not they had taken care of their mother with breast cancer or had had their mother die from the disease. Consistent with previous research, results indicated that FH+ women whose mothers had died of breast cancer had significantly higher breast cancer-related distress than either FH+ women whose mothers had not died of breast cancer or FH- women ( $p < .05$ ). Further analyses revealed that FH+ women who had cared for their mothers with breast cancer had higher cancer-related distress than women who did not ( $p < .01$ ), and that FH+ women whose experience included both caregiving and the death of their mother from breast cancer had the highest levels of cancer-related distress ( $p < .01$ ) and depressive symptoms ( $p < .05$ ). Findings also indicated that FH+ women with heightened perceptions of risk for breast cancer had higher levels of distress, independent of past stressors. These findings suggest that psychosocial interventions for women with family histories of breast cancer might be appropriately focused on these issues.

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## INTRODUCTION

Having a family history of breast cancer (FH+) is a significant risk factor for the development of the disease. Epidemiological studies have indicated that healthy women who have one or more first-degree relatives diagnosed with breast cancer are at two- to three-fold risk of developing breast cancer themselves (1). As FH+ women must live with the increased threat of developing breast cancer, researchers have hypothesized that they may experience elevated levels of psychological distress. Consistent with this possibility, early case reports by Hyland et al. (2) suggested that women with family histories of breast cancer exhibit symptoms of anxiety and poor psychological adjustment, possibly because of distress over meeting the same fate as their family member(s).

More recent empirical studies have generally corroborated these initial clinical impressions, providing evidence that FH+ women experience elevated levels of both cancer-specific and generalized psychological distress (3-8). For example, a number of studies by Lerman and colleagues (3-5) report elevated levels of general psychological distress in FH+ women recruited with family members in active treatment, and two of those studies report elevated levels of cancer-specific distress, as demonstrated by intrusive thoughts about breast cancer. A recent report from our group (6) comparing FH+ women to a concurrently assessed comparison group of FH- women from the same community indicated that FH+ women experienced higher levels of both cancer-specific and general psychological distress than did FH- women, even though they all had been recently informed that their mammography results were normal and their affected relatives had not been in active treatment for at least 6 months.

Although the preponderance of data appear to support the view that FH+ women are generally more distressed than FH- women, a few studies have highlighted the variability in levels of distress. For example, Wellisch et al. (9) and Lerman et al. (3) noted large individual differences in levels of distress among FH+ women, with some women reporting little or no distress. Individual differences in distress among FH+ women have been proposed as one explanation for occasional failures to detect differences in distress between FH+ and FH- women (e.g. [9]).

Surprisingly few studies have examined predictors of psychological distress in FH+ women. In one recent study from our group, Zakowski et al. (10) hypothesized that, in addition to perceptions of future breast cancer risk, exposure to past cancer-related events might be related to distress in FH+ women. Consistent with that hypothesis, that study revealed that not only was perceived breast cancer risk associated with increased distress in FH+ women, but FH+ women who had had a parent die of cancer also exhibited elevated levels of distress. These results underscored the potential impact of women's individual experiences related to their family histories of breast cancer. One related experience likely to have a powerful impact is having served as a caregiver to a mother with breast cancer. Support for this possibil-

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ity comes from an extensive body of literature indicating that caregivers experience considerable psychological distress, particularly depressive symptoms, which may persist long after the interval during which the caregiving had occurred (e.g. 11,12). Indeed, recent theorizing (13) has argued that the dual process of caregiving and death of a family member as a result of serious disease can have a profound psychological impact. Other theorists (14) have also more generally emphasized the potential negative effects of past stressors in combination with concerns about future events related to the source of past stress. Following these lines of reasoning, we hypothesized that: (a) past cancer-related events (i.e. maternal breast cancer caregiving and death, "Looking Back"), and (b) perceptions of future personal risk for developing breast cancer ("Looking Forward") would predict current levels of distress.

A number of studies have also raised the possibility that the timing of a stressful life event, specifically one's age at the time and the recency of the event, may affect subsequent distress levels (10,15). Research on FH+ women has also suggested that chronological variables related to a mother's disease may be related to distress levels. For instance, Wellisch et al. (15) found that the recency of maternal diagnosis predicted current distress in daughters of breast cancer patients. On the other hand, Zakowski et al. (10), when examining the relations between distress and chronological variables, found that mother's age at the time of cancer death, daughter's age then, and recency of death did not predict daughter's distress. As chronological variables have not been well-studied to date and may be potentially important predictors of distress in FH+ women, we explored the possibility that such variables would impact distress.

The purpose of the present study, then, was to replicate the previous findings from our group on the impact of parental cancer death on distress in an independent sample of women, and to extend previous research by contemporaneously examining the potential impact of caregiving, as well as maternal breast cancer death and perception of future risk, on psychological distress. A better understanding of the impact of these cancer-related variables would provide information useful for appropriate targeting of interventions to the FH+ women likely to experience the highest levels of psychological distress.

## METHOD

### Subjects

One hundred forty-eight women with ( $n = 57$ ) and without ( $n = 91$ ) first-degree relatives with breast cancer participated in the study. Subjects were recruited as part of a larger study by advertisements placed in three medical centers in New York City requesting participants for a study of mind-body effects and family history of breast cancer. To accrue sufficient numbers of FH+ women, we oversampled for women who had family histories of breast cancer. Fewer than 10% of women refused to participate once contacted. To reduce sample heterogeneity, all women were healthy by self-report with no personal history of cancer or other serious chronic illness (e.g. diabetes) at the time of the assessment. Women were assessed no earlier than 1 month after a cancer screening appointment to minimize acute screening-related anxiety. Additionally, women with family histories of breast cancer were excluded if their relative had been in active treatment for breast cancer within the previous 6 months. Mean age of the sample was 42.4 years ( $SD = 10.8$ ). Over a third of the sample had family histories of breast cancer; a third had objective risk estimates of greater than 11% according to the Claus et al. (16)

formulation of familial risk based on pedigree analyses. Most were minority participants (75% African-American, 10% Hispanic, 1% Asian, 1% Native American). Over a third had completed college; a third were currently married. Mean age at menarche was 12.5 ( $\pm 2.0$ ), mean age at first live birth was 22.0 ( $\pm 5.0$ ), and mean number of children was 1.1 ( $\pm 1.8$ ).

### Measures

Subjects completed questionnaires assessing demographics and family history of cancer. They also reported possible risk factors for breast cancer, including age at menarche, age at first live birth, and number of children (17). Additionally, the family history questionnaire assessed whether or not the participant's mother had died of breast cancer and whether or not the participant had served as a caregiver during her mother's illness (Did you take care of your mother [emotionally or physically] when she had cancer? Yes/No).

General psychological distress over the past 3 weeks was measured using the Brief Symptom Inventory (BSI) (18). The BSI has nine subscales and three global distress indices.  $T$ -scores of 60 or above on the BSI scales are regarded as clinically significant, and  $T$ -scores of 63 and above are regarded as sufficiently severe to raise the possibility of a psychiatric diagnosis (18). To reduce the possibility of Type I error, we only used one global distress index (the Global Severity Index [GSI]), as well as the depression and anxiety subscales. Consistent with previous research (3,6), cancer-specific distress over the past 3 weeks was measured using the Impact of Events Scale (IES) (19), which is comprised of two subscales: intrusive thoughts and avoidance. "Breast Cancer" served as the "event" on the IES. Finally, subjects reported how likely they felt they were to develop breast cancer sometime during their lives, on a scale of 0% (*not at all likely*) to 100% (*extremely likely*) (6,10,20).

### Procedures

Subjects provided written informed consent prior to participation. Questionnaires were completed in the presence of an investigator who was available to clarify any items, though they were permitted to complete the demographic portion of the questionnaire at home and return it in a prepaid mailer. Subjects were offered \$20 plus the cost of public transportation to and from the study visit.

### Data Analysis

Similar to the methodology of Zakowski et al. (10), we divided the FH+ women into two subgroups: (a) women whose mothers died of breast cancer (the "FH+Death+" Subgroup;  $n = 20$ ); and (b) women whose mothers did not die of breast cancer (the "FH+Death-" Subgroup;  $n = 37$ ). We then divided the FH+ women into two additional subgroups cutting across the FH+Death+/- grouping factor: (a) women who served as caregivers for their mothers with breast cancer (the "FH+Care+" Subgroup;  $n = 36$ ); and (b) women who did not serve as caregivers to their mothers with breast cancer (the "FH+Care-" Subgroup;  $n = 21$ ), yielding a  $2 \times 2$  ("Death  $\times$  Care") factorial analysis of variance (ANOVA) model. In addition, we compared these subgroups of FH+ women to a "Control" group of FH- women ( $n = 91$ ). Family history was not included as a factor in the ANOVA model because a FH- woman by definition could not have experienced her mother's breast cancer death nor cared for her when she had breast cancer. Mothers' mean age at diagnosis was 51.4 years ( $SD = 12.4$ ), subjects' mean age at the time was

25.4 years ( $SD = 13.2$ ), and the diagnosis had been made an average of 16.1 years earlier ( $SD = 11.4$ ). The FH+Death+ Subgroup of women was an average of 26.9 years of age ( $SD = 12.0$ ) when their mothers died of breast cancer, and their mothers were 52.6 years of age at the time ( $SD = 9.6$ ). The death (cutting across Care Subgroups) had occurred an average of 14 years ( $SD = 9.9$ ) prior to the study. The Care+ Subgroup of women was an average 32.3 years of age ( $SD = 12.2$ ) at the onset of caregiving for mothers who averaged 55 years of age ( $SD = 12.7$ ). The onset of caregiving (cutting across Death Subgroups) had occurred an average of 10.9 years ( $SD = 8.8$ ) prior to the study. As mentioned previously, we examined the possibility that chronological variables predicted distress among FH+ women. Finally, as Zakowski et al. (10) suggested that perceived risk for developing breast cancer may mediate the relations between parental cancer death and distress, we included a mediational analysis (21) in our study as well.

## RESULTS

### Group Characteristics

Before we conducted our primary analyses, we compared the demographics of the FH+ and FH- groups to examine possible confounds. These groups did not differ in age, ethnicity, education level, or income level. Because some trends ( $p < .20$ ) toward subgroup demographic differences were observed (Table 1), we included ethnicity, education, and income as covariates in all subgroup analyses. All statistical values reflect the inclusion of these covariates in the analyses. Means, standard errors, and  $T$ -scores (for BSI indices) of all distress measures are reported for all groups and subgroups in Table 2.

### Comparison of Cancer-Specific and General Distress between FH+ and FH- Groups

Independent sample  $t$ -tests were used to assess differences in distress levels between FH+ and FH- Groups. In contrast with our previous findings with other samples (6,10), women's levels of intrusive thoughts ( $M = 7.3$ ,  $SE = 1.1$ ) and avoidance ( $8.5 \pm 1.3$ ) in the FH+ Group were statistically comparable to levels of intrusive thoughts ( $5.2 \pm 0.8$ ),  $t(146) = 1.56$ ,  $p > .05$ , and avoidance ( $6.4 \pm 1.0$ ),  $t(146) = 1.33$ ,  $p > .05$ , of women in the FH- Group. Similarly, women's levels of general distress ( $0.52 \pm 0.06$ ,  $T = 58$ ), depressive symptoms ( $0.56 \pm 0.09$ ,  $T = 58$ ), and symptoms of anxiety ( $0.57 \pm 0.08$ ,  $T = 57$ ) in the FH+ Group were statistically comparable to levels of general distress ( $0.51 \pm 0.05$ ,  $T = 58$ ),  $t(146) = .15$ ,  $p > .05$ ; depressive symptoms ( $0.51 \pm 0.07$ ,  $T = 57$ ),  $t(146) = .40$ ,  $p > .05$ ; and symptoms of anxiety ( $0.52 \pm 0.07$ ,  $T = 56$ ),  $t(146) = .44$ ,  $p > .05$ , of women in the FH- Group (Table 2).

### Comparison of Cancer-Specific and General Distress between Subgroups

Although we did not detect main effect distress differences between FH+ and FH- women, our FH+ Subgroup analyses were consistent with the findings of Zakowski et al. (10). As indicated in Table 2, the FH+Death+ Subgroup had higher levels of both breast cancer-specific intrusive thoughts ( $10.2 \pm 2.2$ ),  $F(2, 145) = 3.71$ ,  $p < .05$ ; and avoidance ( $12.2 \pm 2.6$ ),  $F(2, 145) = 4.02$ ,  $p < .05$ ; than did both the FH+Death- Subgroup ( $5.7 \pm 1.1$  intrusive thoughts,  $6.5 \pm 1.3$  avoidance), and the FH- Group. Additionally, the FH+Death- Subgroup reported cancer-specific distress levels that were statistically comparable to those of the

TABLE 1  
Demographic Characteristics by Group and Subgroup

	Age Mean (SE)	Ethnicity % Black	Education % High School	Income % > 20 K
FH- ( $n = 91$ )	41.8 (11.0)	75.3	43.5	51.8
FH+ ( $n = 57$ )	43.4 (10.3)	72.8	31.6	69.2
FH+Death+ ( $n = 20$ )	41.6 (9.4)	85.0 <sup>a</sup>	32.4	68.4
FH+Death- ( $n = 37$ )	44.4 (10.9)	65.7 <sup>a</sup>	30.0	69.7
FH+Care+ ( $n = 36$ )	43.7 (9.6)	80.5 <sup>b</sup>	22.2 <sup>g</sup>	70.6
FH+Care- ( $n = 21$ )	42.6 (11.9)	57.9 <sup>b</sup>	47.6 <sup>g</sup>	66.7
FH+Death+Care+ ( $n = 14$ )	41.8 (9.4)	85.7 <sup>c</sup>	21.4 <sup>h,i</sup>	61.5
FH+Death+Care- ( $n = 6$ )	41.2 (10.2)	83.3 <sup>d</sup>	50.0 <sup>h,j</sup>	83.3 <sup>l</sup>
FH+Death-Care+ ( $n = 22$ )	45.0 (9.7)	77.2 <sup>c</sup>	22.7 <sup>j,k</sup>	76.2
FH+Death-Care- ( $n = 15$ )	43.3 (12.9)	46.1 <sup>c,d,e</sup>	46.7 <sup>i,k</sup>	58.3 <sup>l</sup>

Note. Figures with matching superscripts differ at  $p < .20$ .

FH- Group ( $p > .05$ ). The main effects of maternal breast cancer death on general distress, depressive symptoms, and anxiety were not significant.

To address the possibility that maternal death, per se, may account for the observed main effect of maternal breast cancer death on cancer-specific distress, we compared IES scores of women in the FH+Death+ Subgroup to scores of women whose mothers died of causes other than breast cancer ( $n = 80$ ) and women whose mothers were still alive ( $n = 48$ ) in the overall sample. Consistent with the study hypotheses, we found that women whose mothers died of breast cancer had significantly higher intrusive thoughts scores,  $F(2, 145) = 4.27$ ,  $p < .05$ , and avoidance scores,  $F(2, 145) = 4.02$ ,  $p < .05$ , than both women whose mothers died of causes other than breast cancer ( $4.6 \pm 1.0$  intrusive thoughts,  $7.0 \pm 1.4$  avoidance) and than women whose mothers were still alive ( $5.3 \pm 0.9$  intrusive thoughts,  $5.6 \pm 1.0$  avoidance). Simple effects analyses indicated that the latter two groups did not differ significantly from each other ( $p > .05$ ), providing no support for the possibility that maternal death, per se, was responsible for increases in women's cancer-specific distress (IES scores). Including chronological variables (i.e. mother's age then, subject's age then, recency) did not alter these findings.

We also found that the FH+Care+ Subgroup had higher levels of breast cancer-specific intrusive thoughts ( $9.1 \pm 1.5$ ),  $F(2, 145) = 3.67$ ,  $p < .05$ ; and avoidance ( $10.1 \pm 1.8$ ),  $F(2, 145) = 2.57$ ,  $p < .05$ ; than did both the FH+Care- Subgroup ( $4.1 \pm 1.1$  intrusive thoughts,  $5.7 \pm 1.5$  avoidance) and the FH- Group. In addition, the FH+Care- Subgroup reported cancer-specific distress levels that were statistically comparable to those of the FH- Group ( $p > .05$ ). The FH+Care+/-Subgroups did not differ in general distress, depressive symptoms, or anxiety (Table 2). Most interestingly, the results of the Death  $\times$  Care ANOVA within the FH+ Group revealed a significant interaction, such that FH+ women who experienced both maternal breast cancer death and caregiving had higher levels of intrusive thoughts,  $F(4, 52) = 5.08$ ,  $p < .05$ ; and avoidance,  $F(4, 52) = 3.96$ ,  $p < .05$ , than other

TABLE 2  
Means  $\pm$  Standard Errors (and *T*-Scores) of Distress Measures by Group and Subgroup

	Intrusive Thoughts	Avoidance	General Distress	Depression	Anxiety
FH- ( <i>n</i> = 91)	5.2 $\pm$ 0.8	6.4 $\pm$ 1.0	0.51 $\pm$ 0.05 (58)	0.51 $\pm$ 0.07 (57)	0.52 $\pm$ 0.07 (56)
FH+ ( <i>n</i> = 57)	7.3 $\pm$ 1.1	8.5 $\pm$ 1.3	0.52 $\pm$ 0.06 (58)	0.56 $\pm$ 0.09 (58)	0.57 $\pm$ 0.08 (57)
FH+Death+ ( <i>n</i> = 20)	<b>10.2 <math>\pm</math> 2.2<sup>a</sup></b>	<b>12.2 <math>\pm</math> 2.6<sup>a</sup></b>	0.51 $\pm$ 0.06 (58)	0.67 $\pm$ 0.13 (59)	0.59 $\pm$ 0.12 (57)
FH+Death- ( <i>n</i> = 37)	5.7 $\pm$ 1.1	6.5 $\pm$ 1.3	0.53 $\pm$ 0.06 (58)	0.50 $\pm$ 0.12 (57)	0.56 $\pm$ 0.10 (57)
FH+Care+ ( <i>n</i> = 36)	<b>9.1 <math>\pm</math> 1.5<sup>b</sup></b>	<b>10.1 <math>\pm</math> 1.8<sup>b</sup></b>	0.52 $\pm$ 0.06 (58)	0.55 $\pm$ 0.10 (58)	0.60 $\pm$ 0.10 (57)
FH+Care- ( <i>n</i> = 21)	4.1 $\pm$ 1.1	5.7 $\pm$ 1.5 <sup>l</sup>	0.53 $\pm$ 0.13 (58)	0.59 $\pm$ 0.18 (59)	0.52 $\pm$ 0.13 (56)
FH+Death+Care+ ( <i>n</i> = 14)	<b>13.4 <math>\pm</math> 2.8<sup>c</sup></b>	<b>15.4 <math>\pm</math> 3.2<sup>c</sup></b>	0.57 $\pm$ 0.08 (59)	<b>0.81 <math>\pm</math> 0.17<sup>c</sup> (63)</b>	0.64 $\pm$ 0.16 (57)
FH+Death+Care- ( <i>n</i> = 6)	2.8 $\pm$ 1.1	4.8 $\pm$ 2.9	0.35 $\pm$ 0.08 (54)	0.36 $\pm$ 0.12 (54)	0.47 $\pm$ 0.17 (54)
FH+Death-Care+ ( <i>n</i> = 22)	6.4 $\pm$ 1.5	6.8 $\pm$ 1.9	0.49 $\pm$ 0.08 (57)	0.38 $\pm$ 0.12 (54)	0.58 $\pm$ 0.12 (57)
FH+Death-Care- ( <i>n</i> = 15)	4.7 $\pm$ 1.5	6.1 $\pm$ 1.8	0.60 $\pm$ 0.18 (59)	0.67 $\pm$ 0.24 (59)	0.53 $\pm$ 0.17 (56)

<sup>a</sup> Significant Main Effect of Maternal Breast Cancer Death. <sup>b</sup> Significant Main Effect of Caregiving. <sup>c</sup> Significant Death  $\times$  Care Interaction. Bolded figures also differ significantly from FH- Group.

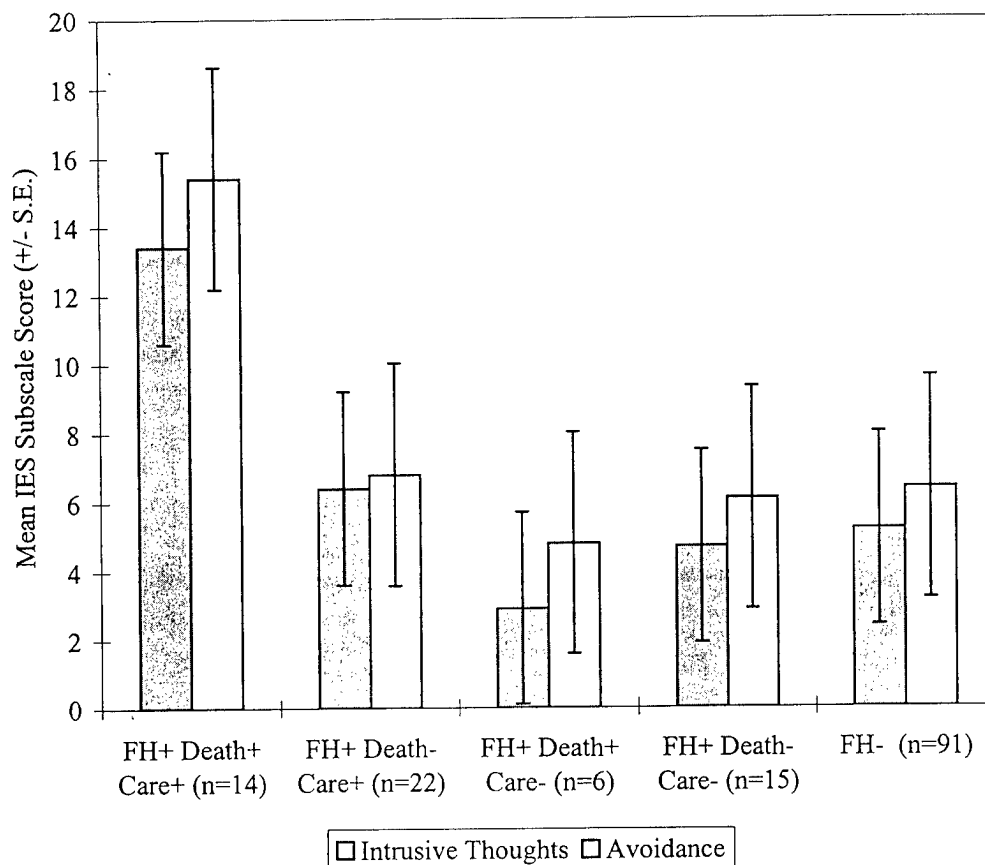


FIGURE 1: Intrusive thoughts and avoidance in FH+ Subgroups and FH- women.

women (see Table 2 and Figure 1). Subgroup comparisons indicated that the FH+Death+Care+ Subgroup experienced higher levels of cancer-specific distress than the other Subgroups and the FH- Group. The other Subgroups of FH+ women reported cancer-specific distress levels that were statistically comparable to those of the FH- Group ( $p > .05$ ). Because one of the Subgroups had a small sample size ( $n = 6$  in the FH+Death+Care- Subgroup), we also compared the FH+Death+Care+ Subgroup to the

combination of the remaining subgroups to reconfirm our findings. Consistent with the findings above, women in the FH+ Death+Care+ Subgroup exhibited higher mean IES scores than the mean scores of the women across all other subgroups;  $t(55) = 3.61, p < .0007$ . Including chronological variables did not alter the above findings.

We performed identical analyses to examine general psychological distress in these subgroups of women. As was the case with

cancer-specific distress, there was a significant Death  $\times$  Care interaction;  $F(4, 52) = 3.47, p < .05$ ; such that the FH+Death+Care+ Subgroup of women had the highest levels of depressive symptoms on the BSI. None of the post hoc subgroup analyses reached the .05 significance level. However, as was the case regarding cancer-specific distress, comparing the FH+Death+Care+ Group to all others combined yielded a significant difference in general distress. Also, the FH+Death+Care+ Subgroup's level of depressive symptoms ( $T$ -score = 63) exceeded normative values (cutoff  $T$ -score = 60), indicating that their distress was clinically significant compared to the general population of adult females (5). Interestingly, the FH+Death+Care+ Subgroup did not evidence higher levels of anxiety or global distress than the other subgroups. As before, including chronological variables did not alter these findings.

#### Perceived Risk as a Possible Mediator of Death/Caregiving and Distress

We examined the possibility that the relations between exposure to past cancer events and current distress may be mediated by the women's current perceptions of future risk for developing breast cancer. Consistent with our previous report (10), within the FH+ Group, perceived risk was positively correlated ( $p < .05$ ) with IES intrusive thoughts ( $r = .33$ ) and avoidance ( $r = .28$ ). Interestingly, perceived risk did not correlate with BSI depression ( $r = .20$ ), but did correlate with global distress ( $r = .27$ ) and anxiety ( $r = .41$ ). The Maternal Death and Caregiving Subgroups, however, did not differ in levels of perceived risk. Following the methodology proposed by Baron and Kenny (21), the present data, thus, did not support a mediational model. Variability in the women's current levels of perceived risk for breast cancer did not account for the relations between current psychological distress and the histories of caregiving and maternal breast cancer death.

#### Chronological Variables Related to Maternal Breast Cancer in the FH+ Group

We explored the possibility that chronological variables pertaining to breast cancer-specific experiences predict current levels of psychological distress. In contrast to the findings of Wellisch et al. (15), mothers' ages at diagnosis were not related to current levels of either cancer-specific ( $r_s = -0.10$  to  $-0.11$ , ns) or general distress ( $r_s = -0.15$  to  $-0.28$ , ns) in the FH+ Group, as indicated in Table 3. Similarly, neither subjects' ages at the time of the diagnosis nor recency of the diagnosis predicted elevated levels of current distress ( $r_s = -0.13$  to  $0.04$ , ns). In the FH+Care+ Subgroup of women, none of the chronological variables (mothers' ages at the time when caregiving began, subjects' ages then, and recency of caregiving onset) predicted elevated levels of current cancer-specific or general distress ( $r_s = -0.26$  to  $0.18$ , ns).

Consistent with our previous report (10), we found that, in the FH+Death+ Subgroup, the women's mothers' ages at death, women's age then, and recency of the death did not predict elevated levels of current cancer-specific distress ( $r_s = -0.33$  to  $0.13$ , ns). Women's mothers' ages at death were, however, significantly negatively correlated with both BSI global distress ( $r = -.52$ ) and anxiety ( $r = -.53$ ) in the FH+Death+ Subgroup of women. To further characterize this relation, post hoc dichotomous analyses revealed that within the FH+Death+ Subgroup, those whose mothers died at an age below the group's median age of death (54 years;  $n = 10$ /group) reported significantly higher

TABLE 3  
Exploratory Correlation Analysis of Cancer-Related Chronology Variables and Distress

	Global		Intrusive		
	Distress	Anxiety	Depression	Thoughts	Avoidance
Maternal Breast Cancer Diagnosis ( $n = 57$ )					
Mother's age then	-.24	-.28	-.15	-.11	-.10
Subject's age then	-.08	-.13	-.02	.02	.04
Years since diagnosis	-.01	-.04	-.07	-.11	-.03
Maternal Breast Cancer Death ( $n = 20$ )					
Mother's age then	-.52*	-.53*	-.12	-.14	-.21
Subject's age then	-.12	-.31	.05	.13	.06
Years since death	-.21	-.02	-.32	-.33	-.26
Onset of Caregiving ( $n = 36$ )					
Mother's age then	-.26	-.26	.05	-.14	-.02
Subject's age then	-.21	-.19	-.03	-.15	-.05
Years since caregiving	.18	.15	.03	-.05	.09

\*  $p < .05$ .

general distress ( $0.59 \pm 0.07, T = 59$  below median age versus  $0.42 \pm 0.10, T = 56$  above median age),  $F(1, 19) = 3.76, p < .05$ , and anxiety symptoms ( $0.91 \pm 0.18, T = 61$  [clinically significant (18)] below median age versus  $0.32 \pm 0.11, T = 52$  above median age),  $F(1, 19) = 4.71, p < .05$ , even after accounting for whether or not they had served as caregivers. These findings suggest that having a mother die of breast cancer at an early age is an independent predictor of high levels of general distress and clinically significant levels of anxiety ( $T > 60$ ).

#### DISCUSSION

Consistent with study hypotheses and a previous report from our group (10), the present study revealed that women with family histories of breast cancer whose mothers had died of the disease experienced higher levels of both breast cancer intrusive thoughts and avoidance compared to other women, even an average of 14 years after the death. Extending our earlier report, we found in this independent sample that women whose family histories of breast cancer included serving as caregivers for their mother with breast cancer experienced heightened levels of intrusive thoughts and avoidance, as well. Perhaps the most intriguing finding, however, was that women who had family histories of breast cancer that included the experience of both having been a caregiver and having their mother die of the disease had the highest levels of both breast cancer-specific distress and general depressive symptoms, while having had one experience without the other did not predict

higher distress than was observed in the Comparison group of women without family histories of breast cancer (see Figure 1). Finally, we found that, independent of caregiving, women whose mothers died of breast cancer at a younger age had higher levels of global distress and anxiety.

In addition to providing evidence that specific past experiences associated with women's family histories of breast cancer ("Looking Back") are strongly predictive of current distress levels, the results of the present study also indicate that women's perceptions of their future risk for developing the disease ("Looking Forward") predict elevations in current levels of psychological distress. In our previous report (10), there was some support for the possibility that the pathway from past breast cancer-related experiences to elevated psychological distress may be mediated by elevated perceptions of one's own future risk for developing the disease. Interestingly, our present data did not support this mediational model; women whose family histories included both serving as a caregiver and maternal breast cancer death did not perceive themselves to be at greater risk for developing the disease. Past experiences and perception of future risk, therefore, were independent predictors of current distress. These findings are consistent with recent theoretical propositions about the dual impact of past and future concerns on current distress (14). It must be noted, however, that we cannot rule out relations between past cancer experiences and other future threats (e.g. expectations for surviving). Alternatively, the potential trauma involved in being exposed to multiple stressors such as maternal breast cancer death and caregiving may be distressing in itself, without a mediating pathway of cognitive appraisal (22). Future research should examine these possibilities.

The present findings are consistent with an established body of research on family caregivers, which suggests that depressive symptoms may persist even long after the cessation of caregiving (11,12). It is important to note, however, that in this first study to investigate the possible impact of caregiving in women at familial risk for breast cancer, we did not thoroughly assess the numerous aspects of the caregiving experience, which may account for additional variation in subsequent distress within this group of women. Recent theorizing (e.g. 23-25) emphasizes the types of caregiving provided (e.g. emotional support, physical assistance, financial support, etc.) as well as the caregiver's reaction (e.g. changes in self-esteem, relationships, depression, guilt, etc.). It must be emphasized, however, that the results of the present study suggest that the simple fact of having served as a caregiver to a mother who died of breast cancer is sufficient to predict levels of both cancer-specific distress and general depressive symptoms, even years after these experiences.

Additional research is needed before we can conclude that the specific experiences of maternal breast cancer caregiving and death are directly related to increased breast cancer-specific distress. Although we found no support for the possibility that death to any cause would have similar effects, we did not collect data on caregiving for causes other than breast cancer. In addition, mothers in the FH+Death+Care+ Subgroup may have been more severely ill. Future research should attempt to determine relations between both objective and perceived maternal illness severity and distress. It should also be noted that the study sample consisted of predominantly non-White women who responded to advertisements posted in medical centers. Studies of women with family histories of breast cancer have typically recruited targeted samples (e.g. relatives of cancer patients) to assure adequate recruitment of

FH+ women. To our knowledge, sampling techniques such as random-digit-dialing have not been employed to study this population. The present findings, in conjunction with previous research on distress among women with family histories of breast cancer, may justify larger scale investigations employing more comprehensive sampling techniques that would confirm generalizability of findings to the population at large. Additionally, whether or not analogous findings of disease-specific distress, caregiving, and death would be obtained in samples of individuals at risk for other diseases has not yet been examined.

In light of earlier studies concluding that women with family histories of breast cancer, as a group, exhibit higher distress levels than women without family histories, it is particularly important to be mindful that great variability exists in these women's distress levels. Indeed, in the present study, unlike previous studies with different samples (e.g. [6]), we did not find a main effect of family history on breast cancer intrusive thoughts or avoidance. The results of this study, thus, suggest the importance of examining factors beyond family history per se, to better characterize predictors of distress. Interventions might be more efficiently focused on women with family histories who cared for a mother who died of breast cancer, women whose mothers died at a younger age, and women who perceived themselves to be at high risk for breast cancer, for whom distress is likely to be highest. Health care providers interacting with the relatives of breast cancer patients may want to consider assessing their experience of specific cancer-related stressors when attempting to identify those most in need of psychological counseling.

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