

# CANCER-SPECIFIC WORRY INTERFERENCE IN WOMEN ATTENDING A BREAST AND OVARIAN CANCER RISK EVALUATION PROGRAM: IMPACT ON EMOTIONAL DISTRESS AND HEALTH FUNCTIONING

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## SUMMARY

Intrusive thoughts about cancer, often identified as 'cancer-specific worries' or 'cancer-specific distress', have been postulated to be associated with dysfunction in women at increased risk of developing breast or ovarian cancer. The current study discusses the development and validation of a measure designed to assess women's perceptions of the interference such worries create in their daily functioning. Analyses revealed that approximately two-thirds of a high-risk breast cancer clinic sample perceived worries about breast cancer as interfering with their functioning across a variety of life domains. Multiple regression analyses indicated that worry interference scores predicted Profile of Mood States (POMS) Anxiety and Confusion, and Short Form-36 (SF-36) Role-Emotional and Mental Health scores after the effects of other variables such as frequency of worry about breast cancer, and having a family history of cancer had been considered. Women who perceived their worries as interfering with their functioning reported higher levels of anxiety and confusion, and diminished mental health and role functioning. The results add to the expanding area of anxiety/distress in at-risk populations by providing (1) a direct measure of the perceived interference associated with breast cancer-specific thoughts, (2) a validation of the measure via its associations with standard measures of emotional distress and health functioning, and (3) evidence of the measure's incremental predictive value in explaining distress and quality of life, after consideration of background variables, such as having a family history of cancer. Copyright © 2001 John Wiley & Sons, Ltd.

## INTRODUCTION

Despite advances in breast cancer prevention, 183000 women will be diagnosed with breast cancer in the United States in the year 2000 (American Cancer Society, 1999). Given the known impact of this disease on quality and length of life, a great deal of research has been conducted on the distress experienced by women with breast

cancer. Many studies have focused on identifying the degree of distress present, factors that may contribute to higher levels of distress, and strategies for ameliorating the deleterious effects of distress in this population (Leinster *et al.*, 1989; Fallowfield *et al.*, 1990; Payne *et al.*, 1999).

More recently, researchers have focused efforts on identifying factors that may be associated with the presence of depression or anxiety in women at the time they are diagnosed with breast cancer, as well as factors that may result in the continued presence of anxiety and depression during recovery. In a recent study, Epping-Jordan *et al.* (1999) reported that low optimism and emotion-focused coping predicted anxiety and depression at diag-

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nosis, while intrusive thoughts and optimism were predictive of anxiety and depression at 3- and 6-months post-diagnosis, respectively.

Another factor that appears to be associated with higher levels of distress in women with and without cancer is having a family member who has had cancer (Kash *et al.*, 1992; Lerman *et al.*, 1993; Valdimarsdottir *et al.*, 1995). In these studies, approximately one out of four women had levels of distress that would potentially benefit from a psychological intervention (Kash *et al.*, 1992), while approximately one out of three reported that their daily lives were affected by worries about breast cancer (Lerman *et al.*, 1993). Consequently, both family history and intrusive thoughts or worries about breast cancer appear to play important roles in the development and maintenance of anxiety and depression both in women currently diagnosed with, as well as those at increased risk for, breast cancer.

At present, genetic testing has become increasingly utilized to identify women at increased risk for breast and ovarian cancer. Numerous studies have reported on the likelihood of being diagnosed with breast or ovarian cancer during one's lifetime following identification of the individual as a carrier of a deleterious mutation in the BRCA1 or BRCA2 genes (Easton *et al.*, 1993; Ford *et al.*, 1994; Miki *et al.*, 1994; Phelan *et al.*, 1996; Struwing *et al.*, 1997). As the literature on breast cancer genetics has become more refined, many studies have begun to document the emotional distress that may accompany being at high risk for breast or ovarian cancer (Audrain *et al.*, 1997; Ritvo *et al.*, 1999, 2000). Paralleling studies on breast cancer patients, the results of studies focused on the high-risk population reveal that although women at suspected risk for having inherited a mutated breast or ovarian cancer susceptibility gene (BRCA or other) have average levels of depression and anxiety (Zakowski *et al.*, 1997; Schwartz *et al.*, 1999), there remains a proportion of women who exhibit significant distress that may interfere with their functioning (Ritvo *et al.*, 1999, 2000).

Since it appears that on average, women at increased risk for heritable breast or ovarian cancer do not evidence high levels of global distress, the focus has shifted toward an examination of 'cancer-specific' distress. Research in this area has primarily been in the form of questions about the intrusiveness of thoughts about cancer during the previous week. The focus is variously on the

individuals' worries about having a diagnosis of breast or ovarian cancer and its consequences or on having a family history of breast cancer (Lerman *et al.*, 1995; Schwartz *et al.*, 1995; Croyle *et al.*, 1997; Zakowski *et al.*, 1997). Unfortunately, responses that individuals may have (such as thought intrusions or avoidance) to a stressful event are not, by themselves, equivalent to or synonymous with distress, 'cancer-specific' or otherwise. We interpret intrusions as cognitive events that may or may not result in emotional distress depending on how they are appraised. It is possible that general distress in women at increased risk for breast cancer is not elevated and that intrusive thoughts, although present, are neither disruptive nor distressing. We also suggest, however, that women at risk may perceive cancer-specific intrusive thoughts as interfering with their functioning and, therefore, may interpret them as distressing. As such, before cancer-specific intrusive thoughts are equated with distress, it may be useful to measure (1) women's perceptions of the impact of such intrusive thoughts on multiple areas of functioning, and (2) the degree of association between this newly-measured impact on functioning and standard measures of dysfunction and distress.

Although recent research has demonstrated that women at increased risk for breast cancer experience cancer-specific worries and intrusive thoughts (Baider and De-Nour, 1997; Zakowski *et al.*, 1997; Epping-Jordan *et al.*, 1999), and have functioning that appears to be disrupted in a variety of areas (Wellisch *et al.*, 1991, 1992), little research has measured the degree to which cancer-specific intrusive thoughts are perceived as disruptive by the women who experience them. The research that has been done in this area has used single-item Likert scales to assess the perceived global impact of cancer worries and intrusive thoughts on functioning (Easterling and Leventhal, 1989; Lerman *et al.*, 1991). More specifically, Easterling and Leventhal (1989) asked women at increased risk to rate the impact cancer worry had on their 'other thoughts and activities', while Lerman *et al.* (1991) asked women to rate the impact of cancer worry on 'mood and daily functioning'. While this information is helpful in that it provides evidence of a perceived association between dysfunction and cancer-specific cognitive processes, single-item scales are limited in the amount of information they convey. We hypothesized that a more detailed measure would

allow for more variability in responses, thereby increasing the descriptive and predictive value of the construct of worry interference, and allowing for a more detailed analysis of putative areas of impairment. To this end, we set out in 1994 to develop a measure to determine whether patients attending a newly-founded breast and ovarian cancer risk evaluation clinic perceived their cancer-specific thoughts as interfering with their functioning in a number of areas. We expected some variability in women's responses to such a questionnaire, and hypothesized that increased interference would be positively related to standard measures of dysfunction and mood disturbance.

## METHOD

### *Participants*

Individuals are both self-referred and referred by medical professionals to the University of Michigan Breast and Ovarian Cancer Risk Evaluation Program (BOCREP) if they have a positive family history of breast or ovarian cancer in one or more close relatives, or a constellation of other personal risk factors leading to a presumed increased risk profile, as determined by the referral source. These patients are not otherwise part of previously assembled familial cancer high-risk cohorts; they have not been subjects in previous cancer genetics research and they were not invited to come to clinic for research purposes. Therefore, while some of these women may be at high-risk for breast or ovarian cancer, they represent a heterogeneous group of women attending a breast and ovarian risk evaluation clinic as opposed to typical familial cancer high-risk cohorts or patients identified exclusively through fixed eligibility criteria for research. A total of 290 women attended the clinic between February 17 1995 and December 31 1999. Per clinic protocol, all of these women returned screening packets that included the Worry Interference Scale (WIS) prior to their appointment and were subsequently evaluated by a medical oncologist and genetic counselor. Of these 290 women, 205 completed all items of the WIS. Following their initial genetic counseling sessions, 88 women proceeded with genetic testing after being identified as high risk based on a pedigree analysis revealing a high likelihood of the presence of a mutation in a cancer susceptibil-

ity gene being present in the family. All 88 of these women received their testing results during a second counseling session conducted 1 month later. Repeat WIS data were requested one month post-counseling and returned by 67 women. Table 1 presents characteristics of participants.

### *Measures*

*Clinic Questionnaire (CQ).* The CQ is a demographic measure provided to all patients prior to their arrival at the BOCREP. Individuals are asked to answer questions that provide information on basic demographics, medical and lifestyle factors, personal and family history of breast cancer, and cancer screening practices.

*Profile of Mood States (POMS).* The POMS is a 65-item self-report questionnaire that measures mood using six scales: Tension–Anxiety, Depression–Dejection, Anger–Hostility, Vigor–Activity, Fatigue–Inertia, and Confusion–Bewilderment (McNair *et al.*, 1971, 1981). Respondents are asked to rate the degree to which an adjective has applied to them during the past week on a five-point scale ranging from 0 'not at all' to 4 'extremely'. A Total Mood Disturbance scale can be computed by summing the subscale scores, weighting Vigor negatively. The POMS has proven reliability and validity and has been used in research with a variety of cancer populations (McNair *et al.*, 1971; Lerman and Schwartz, 1993; Schwartz *et al.*, 1995).

*Medical Outcomes Survey Short Form 36 (SF-36).* The SF-36 is a 36-item questionnaire assessing quality of life (QOL) and functioning across a variety of domains (Ware, 1993). It is composed of eight scales including physical functioning, social functioning, bodily pain, and mental health. A scale total is obtained by summing the responses to each item within the scale. Subsequently, transformed scores are obtained by taking the total score, subtracting the lowest possible total score and dividing by the possible total score range. This number is then multiplied by 100 in order to obtain a transformed score that is between 0 and 100. Transformed scores are reported in the current article. The SF-36 was chosen over several more specific measures of quality of life (e.g. the Functional Assessment of Cancer Therapy—FACT—or Functional Living

Table 1. Demographic characteristics of sample ( $n = 290$ )

	<i>n</i>	%	<i>x</i>	S.D.
Age			43.27	10.52
Ethnicity				
Caucasian	205	70.7		
African-American	4	1.4		
Native American	1	0.3		
Hispanic	1	0.3		
Asian	2	0.7		
Unknown, not asked, missing or other	77	26.5		
Religion				
Catholic	54	18.6		
Jewish	24	8.3		
Protestant	83	28.6		
Unknown, not asked, missing or other	129	44.4		
Marital status				
Single	24	8.3		
Married	167	57.6		
Separated, divorced, or widowed	24	8.3		
Unknown, not asked, missing or other	75	25.8		
Education				
Completed or attended high school	29	9.9		
Completed or attended college	87	30.0		
Completed or attended graduate school	98	33.8		
Unknown, not asked, missing or other	76	26.2		
Cancer Hx.				
Self				
Yes	56	19.3		
No	200	69.0		
Did not report	34	11.7		
Family				
Yes	197	67.9		
No	39	13.4		
Did not report	54	18.6		

Index-Cancer—FLIC) because of the desire to obtain a measure of initial health functioning when individuals may not have a diagnosis of cancer. It has demonstrated adequate reliability and validity (Ware, 1993).

*Worry Interference Scale (WIS)*. The WIS is a seven-item self-report measure developed by the authors to assess the degree to which thoughts about breast cancer are perceived as interfering with the respondents' daily functioning. It is imbedded within a larger questionnaire that also assesses perceived risk, intent to undergo genetic testing, and frequency of worry about getting breast cancer. The WIS scale items assess disruptions in sleep, work, concentration, relationships,

having fun, feeling sexually attractive, meeting family needs, and reproductive decisions. Additional items assess participants' abilities to speak with their partners about their concerns, their partners' abilities to be understanding, and frequency of participants' worries about their children's or grandchildren's chances of developing breast cancer. As noted in the discussion of the scale development, these latter three items were removed from the final scale. All items are assessed on a five-point multiple-choice scale ranging from 1 'not at all' to 5 'a lot'. As such, the range of scores on the total scale is 7–35. Examples of items include 'Fears of developing breast cancer have affected my relationships with others', 'Thoughts of breast cancer have affected

my ability to sleep', and 'Worries about breast cancer have affected my ability to meet the needs of my family'. A 'not at all' response is considered to mean either that the respondent does not experience worry about getting breast cancer or that worries about breast cancer do not interfere with her functioning. Validity and reliability data, as well as information on scale development are provided as part of the results of this report. Frequency of worry about breast cancer is measured on the same five-point scale as the interference items, with responses ranging from 1 'not at all' to 5 'a lot'. Results of analyses conducted with perceived risk and intent to undergo genetic testing are currently being prepared for a future manuscript and will not be presented here.

### *Procedure*

Upon making initial contact with the BOCREP, individuals are sent a questionnaire package that includes the CQ and the WIS (Time 1). Returned questionnaires are examined and appointments are made for those women who appear to have concerns that can be addressed by the clinic. At the time of the appointment, and before counseling, individuals complete a questionnaire package that includes the POMS and SF-36, among other measures. In the current study, following completion of these questionnaires, individuals are provided with risk assessment, genetic counseling, and risk management options; in the course of the session, if pertinent, a discussion of whether they desire and/or qualify for genetic testing ensues. Blood is drawn for those who are interested in and qualify for testing. One month following their appointment, patients are asked to complete a second package that includes the WIS (Time 2) and to return the package by mail. If genetic testing has taken place, patients are provided the results in a face-to-face post-test counseling session. In the current study, 290 women provided Time 1 questionnaire data, 205 of whom provided complete WIS data. Of these, 67 returned Time 2 follow-up data.

## RESULTS

### *WIS scale development*

*Item generation.* Eleven items assessing interference in functioning were originally considered for

inclusion in the WIS. These items were arrived at through interviews with women attending the BOCREP and from reports in the literature of putative areas of impaired functioning in women with family histories of breast cancer (e.g. Wellisch *et al.*, 1991, 1992). Care was taken to sample a variety of relevant content areas and to vary the language used in the phrasing of the questions. As previously noted, the potential WIS scale items assessed disruptions in sleep, work, concentration, relationships, having fun, feeling sexually attractive, meeting family needs, and reproductive decisions. Additional items assessed participants' abilities to speak with their partners about their concerns, their partners' abilities to be understanding, and frequency of participants' worries about their children's or grandchildren's chances of developing breast cancer. Pearson product-moment correlations between all potential WIS scale items at Time 1 (pre-session) are presented in Table 2.

*Factor analysis.* Factor analysis was conducted in order to reduce the dimension of the data and create a single scale of perceived Worry Interference. In order to create this single summary scale, a procedure recommended by Tabachnick and Fidell (1996) was followed, using Principal Components Analysis (PCA) on a subset of correlated items with pairwise correlations above 0.3. Seven worry interference items assessing dysfunction in relationships, sleep, work, having fun, feeling sexually attractive, meeting family needs, and concentration met this criteria. Analysis of Time 1 data yielded a single factor accounting for 62.7% of the variance in scores. All seven items loaded above 0.7 on the factor, and analysis of the scree plot confirmed the appropriateness of the single-factor solution. Factor loadings are presented in Table 3. Confirmatory analyses conducted on Time 2 data yielded an identical factor solution. Given the stable factor structure of the scale, scores on the seven items were summed to yield a total Worry Interference score, which was used as a summary measure in all further analyses. Frequency data on WIS total scores are presented in Table 4.

*Scale reliability and internal consistency.* The resulting seven-item scale has excellent internal consistency, with Cronbach's alpha coefficients ranging from 0.89 to 0.94 in random samples of clinic patients, where scales with an alpha  $\geq 0.75$  are considered internally consistent (Nunnally,

Table 2. Zero-order correlation matrix for eleven original scale items at Time 1 ( $n = 205$ )

	Relationships	Sleep	Talk to partner	Partner understands	Work	Offspring's risk	Have fun	Feel sexually attractive	Meet family needs	Concentrate	Have children
Relationships	0.47**										
Sleep	-0.05	-0.15*									
Talk to partner	-0.11	-0.16*	0.74**								
Partner understands	0.45**	0.60**	0.0	-0.04							
Work	0.18**	0.25**	0.02	-0.04	0.22**						
Offspring's risk	0.64**	0.56**	-0.03	-0.08	0.64**	0.27**					
Have fun	0.51**	0.49**	-0.11	-0.10	0.52**	0.27**	0.63**				
Sexually attractive	0.50**	-	0.02	-0.06	0.62**	0.19**	0.59**	0.49**			
Family needs	0.49**	0.60**	-0.06	0.08	0.70**	0.17*	0.64**	0.50**	0.66**		
Concentrate	0.27**	0.15*	-0.11	-0.19**	0.31**	0.19**	0.18**	0.23**	0.20**	0.23**	
Have children											

\*  $p < 0.05$ ; \*\*  $p < 0.0005$ .

Table 3. Factor loading on the WIS

Variable	Factor loading
Relationships	0.765
Ability to sleep	0.789
Work	0.828
Ability to have fun	0.845
Ability to feel sexually attractive	0.740
Ability to meet family's needs	0.785
Ability to concentrate	0.843

1967). Split-half reliabilities range from 0.83 to 0.92 for the first four items and 0.75 to 0.83 for the last three, where split-half reliabilities of at least 0.75 are considered internally consistent (Nunnally, 1967). Test-retest reliability was adequate at  $r = 0.727$  from Time 1 to Time 2 for those women who completed both measures.

*Central tendency.* Scores on the WIS can range from a low of 7 if an individual answers 'not at all' to a high of 35 if a participant answers 'a lot' to all five items. Respondents' scores on the devised scale ranged from a minimum of 7, indicating no interference to a maximum of 34, indicating significant disruptions in every area of

Table 4. WIS total score frequencies

WIS total score	Frequency (n)	Percent (%)
7	71	34.6
8	27	13.2
9	22	10.7
10	13	6.3
11	12	5.9
12	15	7.3
13	4	2.0
14	6	2.9
15	9	4.4
16	7	3.4
17	2	1.0
18	2	1.0
19	2	1.0
20	3	1.5
21	3	1.5
22	1	0.5
23	1	0.5
25	3	1.5
26	1	0.5
34	1	0.5
Total	205	100

functioning assessed. The average interference score was 10.47, indicating at least minimal interference in three areas of functioning, or 'a lot' of interference in one area. However, the standard deviation for this score was 4.58, reflecting a wide variability in the degree to which women perceived breast cancer-specific worries as disruptive of their daily activities. The median score was 9, indicating that approximately half of the women either perceived at least 'a little' interference in two of the seven areas of functioning assessed, or greater interference in one area alone.

*Group creation.* Analyses were then conducted in relation to a dichotomous representation of pre-session Worry Interference, with Group 1 including patients whose worries did not interfere at all with their functioning (34.6%) and Group 2 including patients whose worries interfered 'at least a little' in one or more areas of functioning (66.4%). Comparisons between the two pre-session Worry Interference groups on baseline demographic variables such as age, marital status, religion, ethnicity, and education did not reveal any significant differences that might explain higher Worry Interference in some patients.

*Correlations with Worry Interference: convergent validity*

Given the non-normal distribution of scores on the WIS, in order to perform further analyses addressing the validity of the new scale, scores from participants in Group 1 (those indicating no perceived interference from breast cancer worries) were dropped out, and subgroup analyses were conducted on data from Group 2 (i.e. those indicating some perceived Worry Interference). In order to assess the convergent validity of the new scale, Pearson product-moment zero-order correlations were conducted on data from the WIS, POMS, and SF-36. Convergent validity is assessed based on the associations between similar measures, with higher correlations indicative of greater convergent validity. All correlations were in the expected directions.

Worry Interference scores were significantly positively correlated with POMS Anxiety ( $r = 0.331, p = 0.016$ ), Depression ( $r = 0.395, p = 0.002$ ), Confusion ( $r = 0.304, p = 0.021$ ), and Total Mood Disturbance ( $r = 0.388, p = 0.004$ ). WIS scores were also significantly negatively associated with SF-36 scores measuring Mental

Health Functioning ( $r = -0.273$ ,  $p = 0.007$ ), Emotional Role Functioning ( $r = -0.278$ ,  $p = 0.005$ ), and Physical Role Functioning ( $r = -0.200$ ,  $p = 0.045$ ). A trend toward a negative association with POMS Vigor was also observed ( $r = -0.254$ ,  $p = 0.056$ ).

### Worry Frequency

As previously noted, how frequently a woman worried about breast cancer was assessed on a scale that ranged from 'never' to 'at least daily'. Results in the current study revealed that 14% of participants said they never worried about breast cancer, 20.9% seldom worried, 27.9% worried at least monthly, 34.9% worried at least weekly, and 2.3% worried daily. Further examination of Worry Frequency with Group 1 and Group 2 revealed that all women who reported never worrying about breast cancer were in Group 1.

### Effects of cancer on Worry Interference

Prior to examining the effects of Worry Interference on emotional distress and health functioning, the impact of a diagnosis or family history of cancer on Worry Interference was assessed. Chi-square analyses were conducted comparing participants currently diagnosed with breast cancer to those without a cancer diagnosis. Results indicated that women with breast cancer (whether invasive or non-invasive) were more likely to be represented in Group 2 (that is, to have interference in their lives from cancer-specific worry:  $\chi^2 = 14.94$ ,  $p < 0.001$ ). Chi-square analyses were then conducted comparing Worry Interference groups for those whose family members (mothers and/or sisters) had breast or ovarian cancer with those who did not. Analyses revealed no significant differences in the number of family members with cancer between these two subgroups.

### Effects of Worry Interference

*Emotional distress.* In order to determine whether differences in emotional distress existed between those individuals who reported no interference from breast cancer worry (Group 1) and those who perceived some interference (Group 2), POMS scale scores (Anxiety, Depression, Anger, Vigor, Fatigue, Confusion) and Total Mood Dis-

turbance score were subjected to one-way analysis of variances (ANOVAs) by group. Results revealed that Anxiety,  $F(1,81) = 6.22$ ,  $p < 0.015$ , and Confusion,  $F(1,91) = 8.90$ ,  $p < 0.004$ , were significantly different for the two groups. Observed means indicated that individuals in Group 2 (those whose worry interfered with their functioning) reported higher levels of anxiety and confusion. ANOVAs on the remaining scales did not detect statistically significant differences between Worry Interference groups.

Of interest was whether the observed effects of Worry Interference on emotional distress remained significant after consideration of the effects of other variables. In particular, demographic variables such as having a personal or family history of breast or ovarian cancer, or psychological variables, such as the frequency of the respondent's worry about cancer could account for some of the effects noted above. In order to address this, analyses were conducted with age, education, religion, ethnicity, marital status, and Worry Frequency scores as independent variables in bivariate regressions with POMS Anxiety and POMS Confusion as dependent variables. Any variable associated with scores on either POMS Anxiety or POMS Confusion at  $p < 0.10$  was to be controlled for in a multiple hierarchical regression model with Worry Interference. None of the potential confounding variables were associated with scores on the dependent variables of interest at  $p < 0.10$ . Bivariate regression analyses were, therefore, conducted separately on POMS Anxiety and Confusion with Worry Interference as the independent variable. Worry Interference was significantly associated with POMS Anxiety  $F(1,81) = 6.643$ ,  $p < 0.012$  and POMS Confusion  $F(1,91)$ ,  $p < 0.014$ .

*Health functioning.* The two Worry Interference groups were also compared using oneway ANOVAs on the SF-36 scales using the transformed scores. The groups differed significantly on the Role-Emotional,  $F(1,159) = 9.59$ ,  $p < 0.002$ , and Mental Health,  $F(1,154) = 9.65$ ,  $p < 0.002$ , scales. Individuals whose worries interfered 'at least a little' with their daily functioning reported lower levels of mental health and role functioning. The remaining SF-36 scales did not differ significantly between the two groups.

As with the POMS scales, significant SF-36 scales were subjected to bivariate regressions to determine whether Worry Interference was



significantly associated with health functioning after accounting for potential confounding variables. Bivariate regressions with Worry Interference as the independent variable and SF-36 Role-Emotional as the dependent variable yielded significant results,  $F(1,158) = 23.765$ ,  $p < 0.0001$ , as did regressions with SF-36 Mental Health,  $F(1,154) = 10.629$ ,  $p < 0.001$ . However, regressions with Worry Frequency as the independent variable also yielded results indicative of potentially significant associative value: with SF-36 Role-Emotional,  $F(1,168) = 5.558$ ,  $p < 0.02$ ; with SF-36 Mental Health,  $F(1,164)$ ,  $p < 0.053$ . As a result, hierarchical multiple regressions were conducted on each of the two SF-36 scales of interest, with Worry Frequency and Worry Interference as independent variables. Worry Interference was entered into the models sequentially after Worry Frequency, to see if inclusion of the interference measure provided incremental associative utility over simple frequency, since this is the more parsimonious and easily measured of the two constructs. For Role-Emotional, Worry Frequency entered on the first step yielded significant results,  $F(1,157) = 6.1$ ,  $p < 0.015$ . The addition of worry interference on the second step accounted for significantly more of the variance in scores on the criterion,  $F_{\Delta}(1,156) = 16.561$ ,  $p < 0.0001$ . Only Worry Interference explained a significant amount of the variance in Role-Emotional scores in the full model; the effects of Worry Frequency dropped out ( $p = -0.012$ , ns). With regard to Mental Health functioning, Worry Frequency as the only predictor variable did not explain a significant amount of the variance in scores on the scale,  $F(1,154) = 2.073$  ns. The addition of Worry Interference explained significant incremental variance in scores on the criterion,  $F(1,153) = 8.642$ ,  $p < 0.004$ , and brought the full model to significance,  $F(2,153) = 5.409$ ,  $p < 0.005$ .

## DISCUSSION

The current study was designed to assess the utility of an investigator-derived measure of perceived interference from cancer-specific worries and intrusive thoughts. Validity data indicate that the measure correlates as expected with measures of distress and dysfunction across a number of areas. Additionally, analyses using a cut-off score to distinguish individuals whose worries interfered

with their functioning from those who reported no interference revealed significant differences in mood and functioning between the two groups.

Specifically, women whose worries interfered with their functioning were generally more distressed as demonstrated by reduced ratings of their mental health functioning on the SF-36. However, using a more specific multi-dimensional scale, current results indicated that they reported higher levels of POMS anxiety and confusion, but not depression or anger. This suggests that the interference from cancer-specific worries experienced by participants in this study may be more a function of anxiety and mild cognitive dysfunction, than general distress. Additionally, women who perceived interference in their functioning as a result of cancer-specific thoughts also reported more limitations in performing their usual roles in and outside the home, as demonstrated by lower Role-Emotional scores on the SF-36. This indicates that the scale was effective in distinguishing women reporting impairments in their abilities to fulfill their usual responsibilities at home and at work from those reporting no such impairments.

Furthermore, the new measure was found to predict distress and functioning scores when other background variables that have been reported to be associated with distress, such as having a personal or family history of cancer, did not. The measure also predicted scores on the SF-36 beyond the effects of frequency of worry about breast cancer. This is an important point, since it indicates that it is more than the amount of time participants spent worrying about getting breast cancer that predicted their functioning. Rather, the increased information contained within the WIS had predictive value beyond simply how much time they worry about cancer.

When interpreting the results reported here, several caveats should be considered. First, the study utilized a cross-sectional design that means that all associations are correlational, and therefore, no claims toward causality can be made. Any references to prediction in the current paper, therefore, refer to statistical prediction, not temporal prediction. It may be that anxiety, confusion, and impaired role functioning precede the occurrence of thoughts about breast cancer among women referred to the BOCREP. If this proves to be the case, the areas of dysfunction found in the current study would not be the result of experiencing cancer-specific worry and

intrusive thoughts, but the reverse. It is also possible that a third factor, unaccounted for in the current study could cause variations in both cognitive processes and dysfunction. Given this, more research is necessary to determine the potential temporal direction of the associations between cancer-specific thoughts and perceived related dysfunction. Longitudinal studies using path analyses will be useful in future work to test the hypothesis that cancer-specific worry or intrusive thoughts in fact precede and/or cause dysfunction.

Second, although the fact that participants were referred for services rather than recruited for research purposes allows generalization of the results to other high-risk clinics, the relative lack of ethnic and economic diversity of the sample limits the generalizability of results to other populations. In particular, the predominantly white and well-educated sample diminishes the potential applicability of the results to the larger population of individuals at risk for breast or ovarian cancer. Future efforts could be aimed at actively seeking referrals from sources with a more ethnically and economically diverse population base to remedy this.

Third, more research is also needed to develop a better understanding of the cognitive and behavioral processes in which many women at risk engage. To this end, associations of the WIS with the Impact of Events Scale (IES) (Horowitz *et al.*, 1979) could prove useful. The IES, a measure that has been used extensively in research to assess the presence of intrusive thoughts and avoidance related to genetic testing, having cancer, and being at increased risk for cancer, primarily assesses for the presence of intrusive thoughts and avoidant behaviors following a traumatic event. The purpose of the current paper was to introduce and validate a new measure of the interference perceived to be caused by cancer-specific thoughts, and as such did not utilize the IES. Future research with both measures may help lead to a more sophisticated understanding of the anxiety experienced by many women at risk, so that maximally useful interventions and counseling techniques might be developed. More research is needed to distinguish specifically the cognitive events experienced by these women from the emotions they experience, the behaviors in which they engage, and the impairments in functioning they experience.

Further research will also be useful in determining whether the disruptions in daily life function-

ing (in relationships, sleep, work, ability to have fun, feel sexually attractive, concentrate, and meet family needs) perceived to be the result of cancer-specific thoughts are associated with effects on health behaviors, risk perception, or decisional outcomes. There is evidence that cancer-related worries are predictive of adherence to recommendations for mammography screening (Stefanek and Wilcox, 1991; McCaul *et al.*, 1996; Diefenbach *et al.*, 1999), breast self-examination (Kash *et al.*, 1992; Brain *et al.*, 1999), and clinical breast examination (Kash *et al.*, 1992). However, the direction of this association remains equivocal; it may be that Worry Interference plays a moderating role in distinguishing women who adhere to screening practices from those who do not.

Finally, the association of Worry Interference scores with increased cognitive dysfunction, as measured by the POMS Confusion scale implies that women at risk do not feel they are functioning cognitively at an optimal level. Such dysfunction could be associated with difficulties participating fully in the genetic counseling process, and in impairments in decision-making, including decisions to have genetic testing or to take prophylactic measures. Evidence exists that anxiety affects decision-making in experimental paradigms (Raghunathan and Pham, 1999), and may play a role in medical decision-making, including selection of prophylactic mastectomy (Margalith and Shapiro, 1997; Karp *et al.*, 1999; Stefanek *et al.*, 1999). If anxiety is interfering in the counseling and decision-making process, the potential exists for it to be reduced or avoided if appropriate interventions can be designed. Specific cognitive-behavioral strategies for dealing with anxious intrusions and worries that have proven efficacy in clinical settings (e.g. Barlow *et al.*, 1998) may prove useful if adapted for use with this population. Additional research aimed at understanding further the cancer-specific cognitions and related areas of dysfunction experienced by women at risk may help to identify methods of alleviating their anxiety, improving their functioning, and maximizing their satisfaction with the genetic counseling and testing process.

Results from this study add to the expanding area of anxiety/distress and genetic testing issues in at-risk populations. Specifically, they address directly the issue of perceived interference from 'cancer-specific' worry or intrusive thoughts, using a measure designed specifically for that purpose. Results confirm previous research

indicating the presence of cancer-specific worry/intrusive thoughts and add empirical support to clinical reports of perceived disruptions in functioning as a result. These findings have implications for literatures on both worry/intrusive thoughts and genetic testing.

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