

## Distress and Psychiatric Morbidity Among Women From High-Risk Breast and Ovarian Cancer Families

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This study assessed psychological distress and psychiatric disorder in high-risk women enrolled in a hereditary breast and ovarian cancer registry, and it evaluated the concordance between self-report data and interview-based psychiatric diagnosis. A sample of 464 women completed the Hopkins Symptom Checklist-25 and were interviewed using modules of the Structured Clinical Interview for DSM-IV. Level of psychological distress and the prevalence of psychiatric disorder were low and in the range that would be expected for a sample of community-residing women. Screening proved inefficient: Less than 10% of distressed women met criteria for a clinical disorder. High-risk women seeking genetic testing in research settings may not require extensive psychological screening and diagnostic assessment. Caution is expressed about possible self-selection biases in women enrolled in hereditary cancer registries.

The mapping of the human genome and the cloning of genes that convey risk for adult-onset diseases raises the possibility of increasingly widespread genetic testing. Consideration of the presumed benefits of genetic testing needs to be balanced by concerns about the psychological and psychiatric morbidity that could result from individuals being provided with potentially devastating information about future threats to their health. Testing will result in many individuals being burdened by the knowledge that they have an increased probability of developing a life-threatening disease long before its likely onset, and yet options for managing this risk are currently limited. Moreover, individual testing results may reveal that other family members are likely to have an inherited susceptibility to cancer, and this could prove to be an additional psychologically threatening prospect.

The need to understand psychosocial issues in genetic testing became more pressing with the cloning of the genes BRCA1 (Miki et al., 1994; Tavtigian et al., 1996) and BRCA2 (Wooster & Stratton, 1995), alterations of which are associated with many cases of early-onset breast and ovarian cancer. BRCA1 mutations

confer an increased risk for breast, ovarian, and prostate cancers. The lifetime risk of breast cancer for a woman with a BRCA1 mutation is in the range of 50%–85%. In women already diagnosed with a unilateral breast cancer, there is also an increased risk for developing disease in the contralateral breast. The risk of ovarian cancer approaches 20%–40% by age 80. BRCA2 mutations are similar to BRCA1 mutations in conferring a 50%–85% lifetime risk for breast cancer in women. The risk for ovarian cancer is lower than that associated with BRCA1, approximately 15%–20% over the lifetime. BRCA2 mutations also appear to be associated with other cancer risks, possibly including pancreatic cancer and other as yet undetermined sites (Ford et al., 1998).

It is estimated that as many as 1 in every 1,000 persons carries an altered gene associated with susceptibility to breast and ovarian cancer (Ford & Easton, 1995). Options for women who test positive for an altered gene include increased surveillance, prophylactic mastectomy, or oophorectomy and, for some, participation in a chemoprevention trial. None of these measures has proven to be entirely efficacious, and all have known limitations (Burke et al., 1997; King, Rowell, & Love, 1993). A retrospective study recently found that prophylactic mastectomy may reduce the incidence of breast cancer and death from breast cancer among high-risk women by as much as 90% (Hartmann et al., 1999). However, a closer look at this study highlights the uncertainty facing carriers of mutations of BRCA1 and BRCA2 in making decisions about how to manage their risk (Eisen & Weber, 1999). First, it is unclear to what extent the benefits observed in a heterogeneous sample of at-risk women extend to carriers of mutations of BRCA1 and BRCA2. It is likely that only a minority of the women in Hartmann et al.'s (1999) study were mutation carriers, perhaps as few as 10% (Couch et al., 1997). Second, in this study, 639 women electing prophylactic surgery resulted in a reduction of deaths only from an expected 20 to an observed 2. Saving 18 lives is important, but the

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This work was supported by U.S. Army Medical Research and Materiel Command Grant DAM17-96-1-6157 and National Institute of Mental Health Center Grant MH52129-06.

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awareness that another 621 women would probably have survived without electing disfiguring surgery may make the choice of prophylactic surgery unacceptable to many women (Eisen & Weber, 1999).

Although genetic screening for risk of breast and ovarian cancer has become available commercially, it is still considered most appropriate for women who are already considered at high risk on the basis of family history because negative test results are not particularly informative for women without a known altered gene accounting for breast cancer in their families. Women with positive family histories have expressed considerable interest in being tested (Jacobsen, Valdimarsdottir, Brown, & Offit, 1997; Lerman et al., 1997; Lerman, Seay, Balshem & Audrain, 1995). To varying degrees, these women will have had experiences with cancer among their close female relatives, and their personal risk will have been made salient for them as they confront the opportunity to be tested. Many will already have a history of breast or ovarian cancer, and they will be seeking testing to determine the risk of cancer in the contralateral breast or in the ovary or to determine if their cancer is associated with an altered gene carrying heightened risk for other family members. Other women seeking testing will not have such a personal history of cancer but, on the basis of their high-risk status, already assume that they have the altered gene and that this is tantamount to having been diagnosed with cancer (Geller et al., 1995).

One key issue is the extent to which high-risk women's existing level of distress or vulnerability to major depression or other psychiatric disorders might impair their ability to become educated, make an informed choice about testing, and use their test results to manage their risk of cancer. There is now one study indicating that genetic testing does not lead to psychological distress, even when patients learn they have a mutation associated with heightened risk of cancer (Lerman et al., 1996). This finding is reassuring, but the research was limited to a distinct group of men and women who had a known genetic basis for the cancer in their families, and who had been participating in genetic studies for a long time. This research report also combined data from men and women in these high-risk families. Women, in general, have higher levels of distress than men, and they can also be expected to be more affected than men by anticipation of testing and receipt of information that they carry a gene associated with heightened risk for breast cancer. In the absence of much experience with women seeking genetic testing for risk of breast cancer, we are forced to draw on other relevant research, such as women anticipating a biopsy and women who have been diagnosed with breast cancer. Also relevant are studies of individuals learning their risk status for illnesses such as Huntington's disease (HD) and HIV.

There have been indications that some women who have a family history of breast cancer are psychologically distressed (Kash, Holland, Halper, & Miller, 1992; Lerman & Schwartz, 1993; Valdimarsdottir et al., 1995). Other studies suggest that women who are awaiting a biopsy because of suspected breast cancer are psychologically distressed (DeKeyser, Wainstock, Rose, Converse, & Dooley, 1998; Hobfoll & Walfisch, 1984). Moreover, several investigators have reported that women with confirmed diagnoses of cancer have elevated rates of clinical depression (e.g., Derogatis et al., 1983; Fallowfield, 1990; Goldberg et al., 1992; Hopwood, Howell, & Maguire, 1991; Maguire et al., 1978). In contrast, some investigators have reported low levels

of psychological distress and clinical depression among women with breast cancer (e.g., Plumb & Holland, 1981; Silberfarb, Maurer, & Crouthamel, 1980; Worden & Weissman, 1977). There have been historic changes in the social and health care milieu within which breast cancer is diagnosed and treated (Andrykowski et al., 1996) that may decrease the associated distress and psychiatric morbidity. Yet the lack of consistent findings in these studies is also undoubtedly due, in part, to the basic methodological weaknesses inherent in much of this research. To be specific, many of these studies involved small samples of women assessed either directly after diagnosis and surgery or during advanced stages of the illness (e.g., Goldberg et al., 1992; Hopwood et al., 1991; Maguire et al., 1978; Pinder et al., 1993; Silberfarb et al., 1980). In addition, researchers have typically relied on self-report assessment in determining psychiatric morbidity (e.g., Goldberg et al., 1992; Hopwood et al., 1991; Pinder et al., 1993). There is a need to distinguish between self-reported distress and interview-based diagnoses of psychiatric disorder (see Coyne, 1994, for an extended discussion). Elevated scores on self-report measures of distress, such as the Center for Epidemiologic Studies—Depression Scale (CES-D; Radloff, 1977), Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and various versions of the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974; Hough, Landsverk, Stone, & Jacobson, 1982), consistently provide overestimates of the rates of diagnosable psychiatric morbidity. However, despite clarification of the distinction between distress and clinical depression (Massie & Popkin, 1998), the confusion of the two remains widespread in the psycho-oncology literature (for recent examples, see Keogh, O'Riordan, McNamara, Duggan, & McCann, 1998; Zittoun, Achard, & Ruzniewski, 1999) and the genetic testing literature as well (Lawson et al., 1997).

Studies of genetic testing for risk of HD and serological testing for HIV suggest that distress and development of psychiatric disorder are not necessary consequences of receipt of positive test findings. Negative emotional reactions may be transient except for some persons who were distressed before testing or who had a past history of depression (Perry, Jacobsberg, Fishman, & Frances, 1990). As in other contexts, current distress may predict later distress (Cramer, 1994; Kaplan, Roberts, Camacho-Dickey, & Coyne, 1987), and a history of depression is one of the most reliable predictors of future risk of depression (Belsher & Costello, 1988; Coyne, Pepper, & Flynn, 1999). Thus, the few studies that included interview-based diagnoses with representative populations have reported low rates of current, but higher rates of past, psychiatric morbidity (Maunsell, Brisson, & Deschenes, 1992; Silberfarb et al., 1980). These studies underscore the importance of assessing both current as well as past psychiatric morbidity, particularly because women with a past psychiatric history who do not have a current disorder may represent a subpopulation vulnerable to negative reactions to testing.

In summary, on an a priori basis, one might assume that anticipation of genetic testing for risk of breast cancer and receipt of results will entail risk of distress and psychiatric disorder. High-risk women suitable for testing may already have elevated distress and rates of psychiatric disorder that would interfere with education and informed consent. On the other hand, review of some relevant literatures raises the possibility that the risk may not be as great as anticipated. With the advent of more widespread testing,

the question of the psychological status of women seeking testing should not be left to conjecture (Botkin et al., 1996; Lerman, 1997). Knowledge of the rates of distress and psychiatric disorder is vital to ascertain the need for psychological screening, to design educational and counseling programs, to estimate the need for auxiliary mental health services, and to evaluate the incremental distress and morbidity occasioned by positive test findings.

The present study examined rates of psychological distress and psychiatric morbidity among a sample of women who were considered at high risk for breast and ovarian cancer on the basis of personal and family history. They had been enrolled in the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and then the University of Pennsylvania Cancer Center registry. Some of these women were deemed at high risk and were eligible for enrollment in the registry because they already had a diagnosis of breast cancer or ovarian cancer and had at least one other family member who had been diagnosed with one of these cancers. These women have a greater likelihood of contralateral breast cancer, ovarian cancer, or both than women without a family history. Other women in this study had not been diagnosed with breast or ovarian cancer themselves but were eligible for enrollment in the registry because they had at least two relatives who had been diagnosed with one of these forms of cancer.

The women were assessed at a time when they were anticipating the offering of genetic testing to them that could reveal whether they had an altered gene associated with increased risk of cancer. The Hereditary Breast and Ovarian Cancer Study was originally conceived primarily as basic research, not as a clinical service, but by the early 1990s, it became possible to perform linkage analyses with a few families so that it could be determined whether a particular member of the family had an increased risk of cancer. Experience disclosing the results of linkage analyses to some of these families highlighted the complex psychosocial issues involved in making such information available (Biesecker et al., 1993). Moreover, it was apparent at the time that a gene associated with increased risk of breast and ovarian cancer would soon be isolated, and more widespread testing would then become possible. A research project was initiated examining psychosocial issues associated with genetic testing in the Hereditary Breast and Ovarian Cancer Study sample of women. The data reported in this article are derived from baseline assessments obtained from these women in the year after the announcement that a strong candidate for the breast and ovarian cancer susceptibility gene, BRCA1, had been identified (Miki et al., 1994) and when the offering of genetic testing was widely expected to be imminent. Moreover, there was the anticipation that BRCA1 would account for more familial breast cancer than actually proved to be the case and that genetic testing would provide more information to these women than it has (Couch et al., 1997).

The first objective of this study was to assess general psychological distress, cancer worries, and current and past psychiatric disorder in women enrolled in a hereditary cancer registry. This is the first study using interview-based diagnoses to supplement self-report data in evaluating high-risk women. A second objective was to evaluate the concordance between self-report data and interview-based current and past psychiatric diagnoses. Self-report screening instruments are economical and readily administered but tend to have the disadvantage of low specificity as a means of

identifying psychiatric cases (Fechner-Bates, Coyne, & Schwenk, 1994). Moreover, the relationship between self-reported distress and depression is not fixed and constant across populations. For instance, a large-scale epidemiological study of adolescents found that the prevalence of elevated scores on the CES-D (Radloff, 1977) was so high (48%) and the prevalence of depression so low (2.5%) that there was little chance-corrected agreement between the CES-D and a diagnosis of depression (Roberts, Lewinsohn, & Seeley, 1991).

The inclusion of both self-report measures and diagnoses based on semi-structured interviews allowed us to examine the performance of the self-report measures for possible use as the first stage of a two-stage strategy for identifying psychiatric morbidity. Furthermore, this comparison allowed us to evaluate the conclusions about anxiety and depression in this population that are being made on the basis of self-report data (Lerman et al., 1996, 1998). The relationship between an elevated score on a measure of distress and a clinical diagnosis can be summarized in terms of the sensitivity and specificity of the self-report measure (Fletcher, Fletcher, & Wagner, 1988; Zarin & Earls, 1993). *Sensitivity* refers to the proportion of persons with a particular diagnosis who also score above a cutpoint on the self-report measure and who are, therefore, correctly identified as disordered by the measure. *Specificity* refers to the proportion of persons without a disorder who score below the cutpoint. For the purposes of evaluating the use of a self-report measure as a screening instrument, an additional summary statistic is informative: the positive predictive value. This value expresses the probability that a patient obtaining a positive screening score will have the disorder and depends on the prevalence of the disorder as well as the specificity and sensitivity of the test (Fletcher et al., 1988).

The substantial number of women in our sample who had a history of breast or ovarian cancer gave rise to a final, auxiliary aim of this research. These women were relatively long-term survivors of cancer. As we noted, much of what is known about adjustment and psychiatric morbidity of persons affected by cancer comes from samples biased toward elevated levels of distress and depressive and anxiety disorders. Our large sample allowed us to examine whether these past results hold for women who have not been recently diagnosed or who, as a group, are not typically in the midst of active treatment or the terminal stages of the disease.

## Method

### *Sample and Recruitment Procedure*

Women participating in the study were drawn from the registry of the Hereditary Breast and Ovarian Cancer Study conducted by the University of Michigan and the University of Pennsylvania Cancer Center. A heterogeneous set of criteria had been applied in the original recruitment of these women to the registry. Women previously diagnosed with breast or ovarian cancer were eligible if they had at least one other family member with one of these forms of cancer. In an effort to capture paternal transmission, some women were enrolled whose family members with breast or ovarian cancer were not first-degree relatives. Also, there was an oversampling of women from families with both breast and ovarian cancer. For women who had not been diagnosed with breast or ovarian cancer, the requirement was that they have two relatives with breast or ovarian cancer. In August 1995, women enrolled in the registry were sent a newsletter informing them of a study aimed at examining the psychological factors

associated with anticipating and receiving genetic testing. The newsletter gave them the opportunity to decline further solicitation concerning this study. Questionnaire packages and consent forms were then mailed to their homes. A cover letter was included explaining to participants that, on receipt of their questionnaires, a researcher would contact them to arrange a telephone interview. The letter emphasized that the information provided would be kept confidential. If a woman did not respond to this mailing by accepting or declining participation in the study, a follow-up letter was sent, and, if there was still no response, attempts were made to reach the woman by telephone. If women elected to pursue the next phase of the study, an appointment was arranged for a telephone interview. When participants were contacted by telephone, they again received an explanation of the voluntary nature of participation. On average, the questionnaires required 30 min to complete, and the telephone interviews lasted approximately 45 min. The interviews were conducted by well-trained interviewers with graduate training in clinical psychology, social work, or nursing. Of the 633 eligible women who were mailed questionnaires, 54 (9%) declined participation. For another 102 (16%) women, either available addresses and telephone numbers were no longer valid or no questionnaire was returned despite efforts to reach them by a follow-up letter and telephone calls. For reasons of confidentiality, we did not reveal the purpose of a telephone call when an answering machine or person other than the prospective respondent was reached. Our sense is that for the most part, this latter group had simply been lost to the registry, rather than representing passive refusals. Of the 477 women who returned a questionnaire, 464 received a telephone interview. The final sample consisted of 211 women with a previous history of breast or ovarian cancer, and 253 who did not have such a history.

### Measures

**Psychological distress.** The 25-item version of the Hopkins Symptom Checklist (HSCL-25) was used to assess psychological distress. The scale uses 10 items from the HSCL-90 anxiety cluster, 13 items from the depression cluster, and 2 additional somatic symptoms (poor appetite; difficulty falling asleep or staying asleep). The same items also appear with inconsequential differences in wording on the Symptom Checklist 90 (Derogatis & Cleary, 1977). Hesbacher, Rickels, Downing, and Stepansky (1978) found that the HSCL-25 correlated highly with the standard 58-item version of the HSCL (Derogatis et al., 1974). The HSCL-25 has been widely used for the psychiatric screening of medical patients (Fink et al., 1995), and, with a cutoff of 44 for caseness, Hough et al. (1982) found that the HSCL-25 was comparable or superior to the CES-D (Radloff, 1977) in detecting psychiatric disorder, depending on the criterion used. There are extensive data using this scale with healthy, physically ill, and psychiatric samples where adequate rates of reliability have been reported (Cohen, Coyne, & Duvall, 1993; Coyne, Kessler, Tal, & Turnbull, 1987; Coyne & Smith, 1991; Cranford, Coyne, Sonnega, & Nicklas, 1998; Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980; Pepper, Coyne, & Cohen, 1996). Consistent with past studies, coefficient alpha for the HSCL-25 was found to be .91.

**Depression screening questions.** Additional self-report screening questions for depression were taken directly from the questions assessing 2-week mood disturbance and associated impairment from the Structured Clinical Interview for DSM-IV (SCID; First, Spitzer, Williams, & Gibbon, 1995). One question inquired whether, in the past 6 months, there had been 2 weeks of depressed mood most of the day nearly every day. Another question inquired whether there had been 2 weeks of markedly diminished interest or pleasure in all, or almost all, activities. If the answer was affirmative to either of these questions, a follow-up question inquired whether there had been treatment or interference in role functioning. Rost, Burnam, and Smith (1993) previously reported sensitivity in excess of .80 and specificity in excess of .90 for the two questions with respect to a simultaneously obtained diagnosis of major depression using the Diagnostic Interview Schedule (DIS; Robins, Helzer, Croughan, & Ratliff, 1981).

Although these figures suggest some promise for these questions as a means of screening for depression, they may have been inflated by their direct correspondence to the questions in the DIS. Unlike the SCID used in the present study, the DIS is basically a lay-interviewer administered questionnaire and does not allow for interviewer probes of responses (Coyne, 1994).

**Breast cancer worries.** Two 5-point Likert-style items ranging from 1 (*not at all*) to 5 (*very much*) assessed how often women worry about developing breast cancer and the extent to which these worries interfere in their lives. These items have been used in a number of studies and have been found to be positively related to both general psychological distress and to cancer screening adherence (Lerman et al., 1991; McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998; Schwartz et al., 1995; Stefanek & Wilcox, 1991). These items were administered only to women without a history of breast or ovarian cancer.

**Interview-based measures of psychiatric morbidity.** Semi-structured interviews were conducted to assess current and past history of depression, anxiety, and alcohol use. Because of its modular construction, the SCID can be adapted for use in studies in which only a particular diagnosis is of interest (First et al., 1995). The mood disorders, anxiety, and alcohol use modules of the SCID were used in this study. The administration of the SCID was done by telephone because many of the participants were from out of state. Previous studies have shown the concordance of telephone-administered diagnostic interviews with face-to-face interviews for assessment of depression (Baer, Brown-Beasley, Sorce, & Henriques, 1993; Kendall, Neale, Kessler, Heath, & Eaves, 1992; Potts, Daniels, Burnham, & Wells, 1990; Wells, Burnam, Leake, & Robins, 1988). Also, Slutske et al. (1998) recently showed that the reliability and validity of alcoholism diagnoses and symptoms by telephone assessment is as good as what is obtained in face-to-face interviews. Concurrent with the present study, we conducted a reliability study comparing interviewers' diagnoses and ratings of diagnosis and depression symptoms with independent raters using 28 audiotapes of telephone assessments. There was 100% agreement for diagnosis and 97% agreement for specific symptoms.

## Results

### Basic Demographics

As can be seen in Table 1, there were no differences between women with and without a history of cancer for the demographic variables, except that women with a history were significantly older. As a whole, the women were in their late forties and were predominantly White (98%), Christian, married, and with an average of two children. One striking characteristic of this group was their high level of education and income. Most women had at least some college, worked outside the home, and had an annual family income that exceeded \$54,000. These results are consistent with previous findings that women who seek genetic testing are generally well-educated and have a higher socioeconomic status (Codori, Hanson, & Brandt, 1994; Kash, Holland, Osborne, Miller, & Rosenthal, 1997). On average, 8.24 years had elapsed ( $SD = 6.50$ ) since the women with a history of cancer were first diagnosed with cancer, indicating that these women were long-term survivors of cancer. Among those who had a history of breast or ovarian cancer, 50% reported unilateral mastectomy, 20% reported bilateral mastectomy, and 17% reported oophorectomy. Among those who did not have histories of breast cancer or ovarian cancer, 1% reported bilateral mastectomy, and 18% reported oophorectomy.

Table 1  
*Basic Demographic Characteristics of the Full Sample and Women With and Without a History of Cancer*

Variable	All women ( <i>N</i> = 464)			Women with a history of cancer ( <i>n</i> = 211)			Women without a history of cancer ( <i>n</i> = 253)		
	<i>M</i>	<i>SD</i>	%	<i>M</i>	<i>SD</i>	%	<i>M</i>	<i>SD</i>	%
Age (in years)	49.0	12.2		51.9 <sub>a</sub>	11.0		46.2 <sub>a</sub>	13.3	
Religion									
Christian			74			70			79
Marital status									
Married or with a partner			83			84			83
No. of children	2.0	1.8		2.0	2.0		2.0	1.7	
Education									
At least some college			80			76			81
Employed outside home			61			57			63
Income	\$54,500			\$54,000			\$54,500		

Note. Means with the same subscript differ at  $p < .01$ .

### Psychological Distress

Table 2 presents findings concerned with self-reported psychological distress for the full sample as well as for women with and without histories of cancer. As can be seen, there were no differences between the two groups on the HSCL-25, and both groups had a mean score below the clinical cutpoint of 44. Overall, only 23% (confidence interval [CI] 19%–27%) of the women scored in the clinically distressed range. By way of comparison, these women were similar or lower than primary medical care samples (Fechner-Bates et al., 1994; Hesbacher et al., 1980) and nearly identical to women recruited for a recent clinical trial at other sites comparing alternative models of pretest education for BRCA1 testing (Audrain et al., 1997). However, the women in the present study were substantially lower in distress than wives of post-myocardial infarction patients (Coyne & Smith, 1991), persons living with a depressed person (Coyne et al., 1987), female congestive heart failure patients and wives of congestive heart failure patients (Cranford et al., 1998), and divorced women who do not have custody of their children (Santora & Hays, 1998).

### Breast Cancer Worries

Women who had never been diagnosed with cancer scored 2.88 ( $SD = 0.98$ ) on the measure of breast cancer worries and 1.65

( $SD = 0.93$ ) on the measure of how much these worries interfered with their lives. Although only 8% of the women endorsed the lowest rating (i.e., *not at all*) of how often they worried about developing breast cancer, most (59%) of the women reported that worries about cancer interfered with their daily lives "not at all." Worries and interference were correlated with each other ( $r = .47$ ,  $p < .001$ ) and with general psychological distress ( $r = .31$ ,  $p < .001$ , and  $r = .30$ ,  $p < .001$ , respectively).

### Psychiatric Disorder

Table 3 presents findings from interview-based measures of current and lifetime psychiatric morbidity, including depression, anxiety, and alcohol abuse. In the overall sample, only five women (1%; CI 0.1% to 2.0%) met criteria for current major depressive disorder, four of whom had histories of cancer. These figures can be interpreted in light of a reported one-year prevalence of major depressive disorder among primary medical care patients ranging from 5% to 14% (Coyne, Fechner-Bates, & Schwenk, 1994; Katon & Schulberg, 1992) and a one-month prevalence of 3% in community samples of women (Regier et al., 1988). Eighty-seven women (18.75%; CI 15%–22%) were found to have a lifetime history of major depressive disorder, 46 of whom (53%) had a history of breast or ovarian cancer. This rate can be compared to a lifetime prevalence of major depression in women of 8% in the Epidemiologic Catchment Area Study (Weissman et al., 1993) and 21% found in the National Co-Morbidity Study (Kessler et al., 1994). Thus, the lifetime prevalence of major depressive disorder for these high-risk women was low and in the range that would be expected for a sample of community-residing women of this age. One woman with a history of cancer and one without this history met criteria for dysthymic disorder. One woman with a history of cancer and two without this history met criteria for generalized anxiety disorder. Three women without a history of cancer met criteria for mixed anxiety and depressive disorder. Only one woman was found to have an alcohol abuse problem, and she did not have a history of cancer.

Table 2  
*Psychological Distress as Measured by the Hopkins Symptom Checklist, 25-Item Version (HSCL-25)*

Psychological distress	All women ( <i>N</i> = 464)	Women with a history of cancer ( <i>n</i> = 211)	Women without a history of cancer ( <i>n</i> = 253)
HSCL-25			
<i>M</i>	37.5	37.7	37.5
<i>SD</i>	9.2	9.2	9.2
% in clinical range (greater than 43)	23	22	24

Table 3  
*Psychiatric Morbidity as Assessed by the SCID*

Psychiatric diagnosis	All women ( <i>N</i> = 464)		Women with a history of cancer ( <i>n</i> = 211)		Women without a history of cancer ( <i>n</i> = 253)	
	No.	%	No.	%	No.	%
Current major depression	5	1.0	4	1.9	1	0.4
Lifetime major depression	87	18.8	46	21.8	41	16.2
Current major depression (mood disorder GMC)	2	0.4	2	1.0	0	0.0
Lifetime major depression (mood disorder GMC)	10	2.0	7	3.3	3	1.2
Generalized anxiety disorder	3	0.6	1	0.5	2	0.8
Mixed anxiety depression	3	0.6	0	0.0	3	1.2
Dysthymia	2	0.4	1	0.5	1	0.4
Alcohol use (current)	1	0.2	0	0.0	1	0.4

*Note.* SCID = Structured Clinical Interview for DSM-IV; mood disorder GMC = mood disorder due to a general medical condition.

### *Performance of Screening Instruments*

Such a low prevalence of current major depression precludes screening instruments from being efficient in identifying cases. A score meeting or exceeding the clinical cutpoint of 44 on the HSCL-25 yielded a sensitivity of 80%, a specificity of 80%, and a positive predictive value of 4% for depression. The respective values for the HSCL-25 with generalized anxiety as the criterion were 100%, 79%, and 3%. The respective values for the HSCL-25 with either depression or generalized anxiety as the criterion were 88%, 93%, and 7%. Women's self-report on a 2-weeks mood disturbance screening question yielded a sensitivity of 60%, a specificity of 86%, and a positive predictive value of 5% for major depression. Little difference was found for including the requirement of a report of impairment for the 2-weeks mood disturbance in the form of seeking treatment or experiencing difficulties in interpersonal functioning. Overall, screening for psychiatric morbidity using a standard self-report measure would be a highly inefficient process in which most women would not screen positive, and the vast majority of those who screened positive would prove to be false positives in terms of psychiatric diagnosis.

### Discussion

The high-risk women in this sample were remarkably free of psychological distress and psychiatric morbidity. These results held for women both with and without histories of cancer. Only the women without histories of cancer were assessed for cancer worries, but these women were found to have little or no interference of cancer worries with their daily lives. Despite their increased risk for breast and ovarian cancer, as well as their repeated exposure to cancer either in themselves or their relatives, these women compared well with women drawn from other samples. They were comparable to and—depending on the comparison sample—had even lower rates of psychological distress and psychiatric disorder than women drawn from primary medical care and community settings. Thus, it appears that these women have no excess of psychological distress that may be attributed to their high risk

status. As they approached the process of counseling, education, and decision making about testing, they were thus not, as a group, impaired by their psychological state.

Our second objective was to examine the performance of self-report measures for the purposes of screening for clinical disorder. There is an absence of past data concerning the relations between distress and psychiatric morbidity among such high-risk women. We found that a low score on a standardized measure of distress was a good indicator that the women were not suffering from major depression or from an anxiety disorder. Yet women scoring above a standard cutpoint were unlikely to meet criteria for a clinical disorder, indicating that the measure had exceptionally low positive predictive value. The positive predictive value of 4% for major depression in the present study is still a fraction of the 15%–30% obtained in primary care populations (Fechner-Bates et al., 1994; Hough et al., 1982). Indeed, a woman screening positive for depression on the self-report measure in the present sample would be no more likely to be depressed than a randomly selected, unscreened woman in the general medical population (Coyne et al., 1994; Katon & Schulberg, 1992). The performance of these instruments in detecting disorder in this study was constrained by the low prevalence of disorder (Elwood, 1993), and it is unlikely that any modifications of the screening instrument would result in substantially improved performance. From a practical standpoint, these results demonstrate that, as a group, the women do not require extensive psychological screening and diagnostic assessment. The routine use of screening instruments would be inefficient in that less than 10% of the women who were distressed would meet criteria for a clinical disorder.

One interpretation of these findings is that women in our sample who screened positive for psychological distress were nonetheless no more likely to be clinically depressed than an unscreened woman in a primary care setting. What are the relevant differences between clinical depression and psychological distress? A diagnosis of depression suggests the likelihood of a debilitating, but readily treatable condition but also one with a high rate of recurrence (Depression Guideline Panel, 1993). Psychological distress

when a clinical disorder has been ruled out is more ambiguous in its implications, and, on a population basis, much of it proves self-limiting and not in need of psychological or pharmacological treatment.

The results obtained in this study have implications for the interpretation of other studies of the adjustment of high-risk women who are anticipating, or who have received, results of genetic testing. Such studies use self-report measures of distress as indices of anxiety and depression, yet elevated scores on such instruments may be even less indicative of psychiatric disorder than has been previously assumed. It is important that claims of clinically significant distress be grounded in comparisons to normative data and that they be backed by evidence that such distress actually reflects impairment or psychiatric morbidity. Thus, a recent article examined persons who are members of families with known mutations of BRCA1 or BRCA2 but who themselves declined testing (Lerman et al., 1998). Concern was expressed that 18% had elevated distress. Yet this rate is lower than a primary medical care sample and is even lower than the baseline assessment of the women in the present sample. Moreover, preliminary findings concerning psychological consequences of genetic testing for risk of breast cancer suggest that there are little enduring effects on levels of psychological distress (Croyle, Smith, Botkin, Baty, & Nash, 1997; Lerman et al., 1996). These results are at variance with what might have been predicted from case reports about offering testing to high-risk families (Biesecker et al., 1993; Dudok deWit et al., 1997; Lynch et al., 1997), but they are consistent with other empirical findings concerning HD (Codori, Slavney, Young, Miglioretti, & Brandt, 1997; Tibben, Roos, & Niermeijer, 1997; Wiggins et al., 1992).

It is premature to come to any final conclusions concerning the adjustment of high-risk women anticipating and receiving genetic testing for risk of breast and ovarian cancer. However, it is also important that emerging data not be dismissed or distorted simply because they contradict preconceived notions. Unfortunately, such dismissal or distortion has sometimes been the case in the literature concerning genetic testing. In genetic screening for both HD and mutations of BRCA1, findings that recipients of positive test results do not experience substantial distress have been minimized and distorted (Lawson et al., 1997; Taylor & Myers, 1997) and even dismissed with arguments "that low scores on 'mental health scales' can reflect opposite conditions. Low scores usually indicate good psychological health; on the other hand, distress may be present, but denied in order to maintain an illusion of mental health" (Dudok deWit et al., 1997, p. 387; see also Dudok deWit et al., 1998). Results obtained in larger scale studies of high-risk persons with standardized self-report and semi-structured diagnostic interviews are to be preferred to results of studies using unvalidated measures and to clinical speculations concerning potentially unrepresentative cases. For instance, the genetic testing literature continues to contain considerable speculation about the risk of so-called survivor's guilt among persons who are not found to have gene mutations associated with heightened risk of disease (Dudok deWit et al., 1998; Huggins et al., 1992; Tibben et al., 1997). This speculation occurs despite the fact that no empirical study has ever yielded evidence that being informed that one does not have a mutation increases distress. Finally, interpretation of empirical data should be informed by relevant norms for measures, known correlates, and base rates of phenomena in relevant popu-

lations. In the present study, high-risk women were found to be relatively free of psychological distress, and elevated psychological distress was associated with a rate of syndromal depressive and anxiety disorders less than the prevalence of these disorders in unscreened general medical populations. This latter finding suggests the need to temper claims about anxiety and depression associated with testing that are made solely on the basis of self-report measures. Moderately elevated distress scores may simply reflect the norms for relevant comparison populations—a possibility needing more attention in studies lacking a comparison group—and endorsement of items indicating worries about disease may indicate understandable concern about their risk status rather than psychiatric symptoms, morbidity, or impairment.

High-risk women recruited to a hereditary breast and ovarian registry for the purposes of research undoubtedly represent a socially advantaged group, and demographic information from the sample bore this out. Additional data from this sample have given further indication of the social resources of this group of women (Coyne & Anderson, 1999). The married women had stable and highly satisfying marriages, and their husbands were supportive and involved in decision making about managing the women's risk status, including genetic testing. Unmarried women in the sample had similarly low levels of distress, and both married and unmarried women had mobilized considerable support from female relatives. These findings give rise to an important caveat about generalizations from women seeking genetic testing in the context of hereditary cancer registries and research protocols to the larger pool of high-risk women in the community. It is possible that women who seek genetic testing in noncommunity medical settings outside of research protocols may differ. Some women may seek genetic testing in the community because they are distressed by a recent medical finding such as an ambiguous lump in the breast or an abnormal pap smear or by a recent death or diagnosis of cancer in a relative. There is evidence that many women with family histories of cancer have not had extensive discussion of the personal implications of this history (Stefanek & Wilcox, 1991). Such women may be particularly ill-prepared for education and decision making concerning genetic testing. Studies of such women seeking testing under those circumstances are sorely needed. We should not accept uncritically the broad generalizability of results of psychological studies of self-selected registry samples in the absence of comparative data.

Requiring that high-risk women seeking predictive testing for risk of breast and ovarian cancer undergo psychological assessment and counseling increases the cost of genetic testing and needs to be justified by data. Moreover, there have recently been null findings concerning the effects of a program offering monthly monitoring of psychological distress and psychosocial intervention for distressed women who have received a diagnosis of breast cancer (Maunsell, Brisson, Deschenes, & Frasure-Smith, 1996). A similar program resulted in negative outcomes for women recovering from myocardial infarction, and the authors suggested that repeated focusing on the women's relatively minor psychological distress may have disrupted their normal coping efforts (Frasure-Smith et al., 1997). These findings are relevant in suggesting that services offered to manage the distress of high-risk women seeking predictive testing for breast cancer must be tailored to their actual, rather than presumed, needs. Given that high-risk women are no more distressed than women in relevant comparison populations, it

may not be reasonable to assume that interventions targeting distress presumed to be associated with high risk status will, on a population basis, bring about a significant reduction in distress. Of course, if an individual woman expresses a need for such services, she should be offered them, but the present data cast doubt that there will be a high need or interest in such services, and this fits with our clinical experience.

One aim of the present study was to establish baseline differences in the adjustment of high-risk women who had histories of cancer versus those who did not. The goal was to provide a means of understanding any changes in the subsequent adjustment of women without histories of cancer who test positive. However, we instead found that the women with histories of cancer were similarly low in distress and psychiatric disorder and that there were no differences between women with and without this history. Indeed, we have produced evidence of good psychological adjustment for long-term survivors of breast cancer with what is perhaps one of the largest samples to receive assessment by psychiatric interview. These results are consistent with past speculations concerning the ability of patients to make a positive long-term adjustment to cancer when they are neither receiving active treatment nor facing the terminal stages of the disease (Massie & Holland, 1990).

Overall, we set out in the larger project from which these data were drawn to examine what was presumed to be the psychological vulnerability of women anticipating genetic testing. What we have ended up demonstrating is the remarkable psychological intactness of these women. Attention can be profitably turned to better understanding why these women defy the not unreasonable assumption that they would be a distressed, depressed, and anxious group. The experience of living with familial risk of cancer may well have organized psychological resources and fostered resiliency that more than compensate for any vulnerability associated with it. Adversity can produce resiliency as well as vulnerability (Schaefer & Moos, 1992; Caspi & Moffitt, 1991), and high-risk women anticipating testing may provide an excellent opportunity to study this.

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Received March 24, 1999

Revision received October 10, 1999

Accepted October 25, 1999 ■

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