

ARTICLES

Cancer Worry in Women With Hereditary Risk Factors for Breast Cancer

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Purpose/Objectives: To investigate symptom-based cancer worry in women who are at hereditary risk for breast cancer, specifically levels of worry, correlations of cancer worry, perceived cancer risk, and clinical signs or symptoms of breast cancer, as well as predictors of cancer worry.

Design: Cross-sectional, correlational.

Setting: Primarily the United States.

Sample: 200 women, aged 18–80, with no personal history of cancer, who met at least one established criterion of hereditary breast cancer risk were recruited primarily from a mammography facility and cancer prevention clinics or via network sampling.

Methods: Completion of the following self-report instruments: Thoughts About Cancer Scale and measures of clinical symptoms, perceived risk, and sample characteristics. Data analysis consisted of descriptive statistics, Pearson correlations, and binary logistic regression.

Main Research Variables: Cancer worry, total clinical signs of cancer, perceived cancer risk, age, and family history.

Findings: Participants sometimes worried about breast cancer but had more general breast cancer worry than worry based on perceived neutral or breast cancer-specific symptoms. Total clinical signs of breast cancer correlated significantly with cancer worry. Women aged 41–50 and those with more clinical signs of breast cancer were 3.76 and 1.49 times more likely to have high worry, respectively.

Conclusions: Moderate worry in high-risk women is not unusual. Total symptoms and younger age predict higher breast cancer worry, whereas perceived risk and family history do not.

Implications for Nursing: Counseling of young, high-risk women should include assessments of worry and clinical signs of breast cancer.

Key Points . . .

- Women with strong hereditary risk factors may not be overly worried about developing breast cancer.
- Worry has not been linked conclusively to practice of risk-reduction behaviors in high-risk populations.
- More research is needed to better understand associations among clinical signs and symptoms, cancer worry, and perceived risk of cancer.

haviors, and well-being. However, associations of cancer worry with these constructs are not straightforward. For example, some studies reported a positive relationship between breast cancer-specific worry and perceived risk of cancer (Bish et al., 2002; Brain, Norman, Gray, & Mansel, 1999; Easterling & Leventhal, 1989; Hopwood et al., 1998; Lloyd et al., 1996), whereas others showed no relationship (Audrain et al., 1997). Likewise, moderate to high levels of cancer worry motivated specific risk-reduction behaviors in high-risk groups (Audrain et al.; Diefenbach, Miller, & Daly, 1999; McCaul, Branstetter, O'Donnell, Jacobsen, & Quinlan, 1998) or inhibited those behaviors (Kash, Holland, Halper, & Miller, 1992; Kash, Holland, Osborne, & Miller, 1995; Lerman et al., 1993). High levels of worry also influenced participation in risk-assessment or cancer-prevention clinical trials (Audrain et al.; Bowen et al., 1999; Brain et al., 2001; Lerman, Rimer,

Cancer worry is a phenomenon receiving heightened scrutiny in the cancer literature, particularly in studies of hereditary cancer predisposition. Predominant risk factors for hereditary cancer predisposition include a strong family history of one type of cancer or constellations of cancers that are signals for certain hereditary syndromes. In these syndromes, cancers usually present in two or more first-degree relatives (e.g., parent, sibling, child) or one first-degree and two or more second-degree relatives (e.g., grandparent, aunt or uncle, niece or nephew), resulting in a pattern of cancer in the family that often spans several generations. Such cancers also may be diagnosed at younger ages than their sporadic counterparts (Lynch & Lynch, 1991). Thus, people at inherited risk for cancer predisposition may worry about not only *whether* they will get cancer, but *when* cancer will occur, thereby providing one explanation for why study of cancer worry is gaining importance.

Cancer worry in individuals at risk for hereditary breast cancer ostensibly affects risk perception, risk-reduction be-



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et al., 1994) or led to excessive self-examination (Brain et al., 1999). In terms of well-being, cancer worry may interfere with functioning (Kash et al., 1992, 1995; Lerman et al., 1993; Trask et al., 2001) and mood (McCaul et al.).

The relationship of cancer worry and symptoms is not well elucidated. The number and frequency of neutral somatic symptoms (e.g., headache, vague aches and pains) elicited worry in some women at high risk for breast cancer, particularly younger women (Cunningham et al., 1998; Easterling & Leventhal, 1989). On the other hand, Chalmers and Thomson (1996) found that at-risk women who were thinking constantly about relatives with breast cancer experienced breast pain that the researchers termed “psychosomatic” in nature. A qualitative study conducted by the current study’s investigator revealed that women with a family history of breast cancer worried that breast changes and generally “feeling bad” were signs of cancer (Loescher, 2001).

Based on the literature and preliminary research, the following definition of cancer worry was formulated for this study: Cancer worry is the extent to which a person thinks about signs or symptoms of cancer that are perceived as real, even if they are not clinically evident. For example, at-risk women who overperform breast self-examination may find breast lumps that cannot be felt by clinicians or they may believe that every ache and pain indicates cancer (Loescher, 2001).

With this definition in mind, the major purpose of this study was to investigate cancer worry in women with hereditary risk factors for breast cancer. Specific aims were to (a) ascertain levels of worry among these women, (b) assess correlations of cancer worry, perceived risk of cancer, and clinical signs or symptoms of breast cancer, and (c) evaluate the ability of clinical signs of cancer, age, and family history to predict cancer worry.

Conceptual Orientation

A model of cognitive determinants of emotion provided the conceptual orientation for this study. In this model, worry depends on two levels of cognition: an abstract, conceptual level and a concrete, perceptual level. Abstract cognition is stimulated by recognition that a threat exists (e.g., being told that a high risk of cancer exists based on family history) and evokes an emotional arousal of worry commensurate with the level of perceived threat. This arousal normally diminishes over time as other concerns occupy the individual’s attention. Recurrence of worry comes and goes and depends on reactivation of the abstract cognition. Reactivating the threat cognition are concrete processes that are stimulated by an environmental or somatic cue, such as a symptom (Easterling & Leventhal, 1989).

Methods

Sample Selection

This cross-sectional study was part of a larger correlational descriptive study that tested a model of perceived risk of hereditary cancer susceptibility (Loescher, 2001). Data from respondents who did not complete all instruments were not included in the final analysis of the larger study. The convenience sample consisted of women aged 18 or older who had no personal history of cancer (except nonmelanoma skin can-

cer), were able to read and write in English, and met at least one of the following criteria for hereditary breast cancer risk (Weber & Garber, 1993): (a) two or more first-degree relatives with a history of breast cancer, (b) one first-degree relative and two or more second-degree relatives with a history of breast cancer, (c) one or more family members diagnosed with either breast or ovarian cancer prior to age 50, (d) one or more family members with bilateral breast cancer, or (e) any family history of male breast cancer.

Participants were recruited from a dedicated mammography facility and cancer-prevention clinics at a comprehensive cancer center. A brochure developed for the study, network sampling (Polit & Hungler, 1995), and the Internet served as additional recruitment strategies. Recruitment occurred from February through December 2000.

Of the 219 eligible women recruited, 16 (7%) chose not to participate. Missing data for three (1%) participants were not reconciled, and these participants were eliminated from the final analysis of all instruments. The final sample consisted of 200 women. Sample size was based on requirements for structural equation modeling, the analysis technique for the larger study.

Instruments

The **Thoughts About Cancer Scale (TACS)** is a newly developed, self-report instrument designed to measure symptom-based cancer worry in people at high risk for breast cancer. The six TACS items were generated from themes in a preliminary qualitative study of women with strong family histories of breast cancer (Loescher, 2001) and a review of the corresponding literature. The items address general breast cancer concerns and worry, neutral signs of worry, and perceived (but not clinically established) breast cancer-specific signs and symptoms, including breast lumps. Because these items were derived largely from qualitative data, content validity was assessed using a procedure described by Imle and Atwood (1988). TACS is scored on a four-point, forced-choice scale, with response options of 1 (rarely or never), 2 (sometimes), 3 (often), and 4 (all the time). Scores are summed to create a single composite index of breast cancer worry. Lower scores (6–11) indicate little worry, and higher scores (12–24) indicate greater worry.

TACS demonstrated acceptable internal consistency for a new scale (standardized alpha = 0.73) (Nunnally & Bernstein, 1994) and adequate stability on retest (intraclass correlation coefficient = 0.83 [95% confidence interval (CI) 0.74, 0.90]) (Streiner & Norman, 1995). Structural equation modeling techniques (Bentler & Wu, 1995) were used to assess construct validity. All model-fit statistics (comparative-fit index = 0.997, Bentler-Bonnet nonnormed-fit index = 0.997, standardized root-mean residual square = 0.027, and root-mean square error of approximation = 0.022) met the criteria for a well-fitting measurement model, indicating that one factor (cancer worry) accounted for the observed covariances among the six items. Factor loadings all were greater than 0.90, providing evidence of construct validity.

Accompanying TACS was a questionnaire designed to elicit information about the characteristics of the sample, including age, marital and educational status, family history of cancer, occupation, financial status, and ethnicity. Perceived risk of cancer was treated as a continuous variable by asking participants to complete the following statement commonly used in assessments of risk perception: “My chance of developing cancer

during my life is ____%.” Participants also responded “yes” or “no” to experiencing any possible common clinical signs of breast cancer since age 18, including having a biopsy of at least one lump in either breast, at least one abnormal mammogram or breast ultrasound, and a breast lump felt during a clinical breast examination or breast self-examination. These values were summed for a total signs score.

Procedure

The University of Arizona Human Subjects Committee approved all study procedures. A consent disclaimer letter accompanied all questionnaires. The committee does not allow investigators to directly contact patients seen at medical facilities, so personnel at the recruitment sources identified and initially contacted potential participants in person or by phone and provided them with summary information about the study. At that time, women desiring more information about the study gave permission to be contacted by the investigator. If these women, or others who self-referred to the study, met the eligibility criteria and were willing to participate, the investigator mailed them a study packet. The packet included the disclaimer letter, questionnaires, and a postage-paid return envelope. All instruments took about 10 minutes to complete. The investigator mailed a reminder to participants who did not return the completed questionnaire packet within three weeks. Nonresponders were considered inevaluable.

Data Analysis

Using the statistical software package SPSS® Version 11.5 (SPSS Inc., Chicago, IL), descriptive statistics were computed to evaluate the data for sample characteristics and responses on the instruments. Associations of absolute perceived risk and specific clinical signs of breast cancer with cancer worry were evaluated with Pearson correlations. Binary logistic regression determined whether selected sample characteristics and total clinical signs of cancer predicted greater worry.

Results

Sample Characteristics

Participants ranged in age from 18–84 years (\bar{X} = 48.6, SD = 14.30), with 102 (51%) in the prime age range (30–50 years) for developing breast cancer associated with hereditary predisposition. Regarding first-degree relatives, 135 participants (68%) reported having a mother who was affected with breast cancer, and 79 participants (40%) had one or more sisters with breast cancer. Almost three-quarters (n = 143, 71%) of the sample had one or more second-degree relatives with a history of breast cancer (see Table 1).

Level of Cancer Worry

The mean total scale score of TACS was 9.7 (SD = 2.6), suggesting that participants’ overall worry about cancer was rarely or never to sometimes. Mean item scores for the six worry items ranged from 1.2 (rarely or never) to 2.3 (sometimes) (see Table 2). Worry was dichotomized into low worry (scores 6–11) and worry at least sometimes (scores 12–24). The majority of participants (55%–87%) had lower scores for items pertaining to neutral symptoms and breast cancer-specific signs and symptoms. Conversely, most participants (81%–86%) reported higher scores for items concerning general breast cancer worry.

Perceived Risk, Signs of Cancer, and Cancer Worry

The mean total score for absolute risk of developing breast cancer was 51% (SD = 24.8). The mean number of signs and symptoms experienced by the sample was 1.6 (SD = 1.5). Table 3 shows individual possible clinical indicators of cancer reported by the sample. Table 4 shows correlations of perceived risk and specific clinical indicators of possible breast cancer with cancer worry.

Predictors of Cancer Worry

Table 5 presents the results of a binary logistic regression predicting cancer worry (1 = low worry or 2 = worry sometimes or more). The independent variables in the equation were total signs, age (18–40, 41–50, or 51+), mother’s breast cancer history (yes or no), number of sisters with breast cancer, and number of second-degree relatives with breast cancer. This model for high and low concerns about cancer was significant (χ^2 = 12.763, df = 6, p = 0.047). Significant explanatory variables of high worry were total clinical signs of breast cancer and participant age of less than 50 years.

Table 1. Sample Demographics

Characteristic	n	%
Age (years)		
\bar{X} = 48.6	—	—
SD = 14.3	—	—
Ethnicity		
Anglo-American	171	86
African American	2	1
Mexican American	6	3
Ashkenazi Jewish	18	9
Other (unspecified)	3	2
Highest level of schooling		
High school or general education diploma	52	26
College	81	41
Postgraduate	66	33
Technical training	1	< 1
Marital status		
Never married	24	12
Married or living as married	136	68
Divorced or separated	28	14
Widowed	12	6
Finances		
Need help	—	—
Check-to-check with debt	16	8
Check-to-check with little or no debt	40	20
Living comfortably	115	58
No financial difficulties	29	15
Occupation		
Homemaker	54	27
Professional	107	54
Skilled laborer	3	2
Unskilled laborer	2	1
Student	16	8
Unemployed	9	5
Retired	9	5
Family history of breast cancer		
Mother	135	68
Affected sisters (one or more)	79	40
Affected second-degree relatives (one or more)	143	71

N = 200

Note. Because of rounding, not all percentages total 100.

Table 2. Level of Cancer Worry in Women at High Risk for Breast Cancer

Worry Indicator	Level of Worry					
	Total Item Score (Range = 1–4)		Low (Score < 12)		At Least Sometimes (Score = 12–24)	
	\bar{X}	SD	n	%	n	%
General worrying about getting breast cancer	2.2	0.79	39	20	161	81
General thinking about own risk of breast cancer	2.3	0.79	30	15	170	85
Thinking she has cancer every time she feels sick	1.2	0.52	161	81	39	20
Overperforming breast self-examination	1.7	0.84	109	55	91	46
Feeling lumps that cannot be felt by healthcare provider	1.2	0.51	173	87	27	14
Thinking every ache and pain is cancer	1.2	0.53	169	85	31	16
Total worry	9.7	2.60	160	80	40	20

N = 200

Discussion

Level of Cancer Worry

The main purpose of this study was to investigate cancer worry in women with hereditary risk factors for breast cancer. The mean total worry score as measured by TACS indicated that women in this study sometimes worried about breast cancer. Several other investigators found comparable levels of cancer-specific worry in similar populations (Audrain et al., 1997; Bish et al., 2002; Bowen et al., 1999; Brain et al., 1999; Diefenbach et al., 1999). However, some investigators (Kash et al., 1992; Lloyd et al., 1996) reported higher, almost clinically pathologic levels of worry in high-risk women, whereas others (Leggatt, Mackay, Marteau, & Yates, 2000) reported rare cancer worry. These studies of cancer worry did not measure worry in terms of signs and symptoms of cancer or base questionnaire items on qualitative data, so, in that regard, the current study presents new information about cancer worry in high-risk individuals.

The low to moderate levels of worry reported in this study may be explained partially by cognitive determinants of emotion. For example, individuals at risk for a potentially life-threatening disease generally do not worry constantly about this threat because they also are dealing with competing concerns and activities that occur as part of everyday living. Additionally, not worrying constantly could be adaptive in that it prevents overwhelming anxiety (Easterling & Leventhal, 1989; Weinstein, 1988; Weinstein, Grubb, & Vautier, 1986). However, gaining a clearer picture of these assumptions would require asking about worry over time, rather than in a cross-sectional fashion. Although women in this study sometimes worried about developing cancer, the absence of a population-based control group precludes comparisons of worry in high-risk women with women at general population risk.

Table 3. Possible Clinical Indicators of Breast Cancer Reported by the Sample

Clinical Indicator	n	%
Biopsy of at least one breast lump	64	32
At least one abnormal mammogram	74	37
Lump felt by healthcare provider	92	46
Lump felt during breast self-examination	85	43

N = 200

On average, participants in this study sometimes worried about developing breast cancer and sometimes thought about their own risk for developing breast cancer. These findings reflect results from other studies (Leggatt et al., 2000; Lerman, Rimer, et al., 1994; McCaul et al., 1998). Many researchers have suggested that this moderate level of worry in women at high risk for breast cancer is the most beneficial—and desired—level for motivating information seeking and practicing recommended risk-reduction behaviors (Bowen et al., 1999; Brain et al., 1999; Lerman, Daly, Masny, & Balshem, 1994). Higher levels of worry actually may be detrimental to these actions and behaviors (Audrain et al., 1997; Diefenbach et al., 1999).

Although women in this study sometimes thought about breast cancer, an unexpected finding was that when taken individually, neutral symptoms and perceived signs and symptoms of breast cancer did not appear to be worrisome. These findings differed from other studies that reported higher worry for high-risk women experiencing neutral symptoms than for women controls (Cunningham et al., 1998; Easterling & Leventhal, 1989). One explanation for low symptom-based worry may be that less than half of the sample reported any clinical signs or symptoms, so the cues for worry did not exist. Another untested explanation may be that the women in this study were recruited largely from a dedicated mammography center and cancer-prevention clinics and already were positioned to deal with any cancer signs and symptoms; therefore, these women experienced less worry.

Cancer Worry, Perceived Risk, and Signs of Cancer

The nonsignificant correlation of perceived risk with cancer worry was not surprising, given the equivocal nature of this relationship in the literature (Audrain et al., 1997; Cull,

Table 4. Correlations of Cancer Worry With Perceived Risk and Clinical Signs of Breast Cancer

Breast Cancer Sign	Total Cancer Worry
Perceived absolute risk	−0.900
Had biopsy of at least one lump	0.169*
At least one abnormal mammogram or ultrasound	0.112
At least one lump felt by healthcare provider	0.108
At least one lump felt during breast self-examination	0.123
Total clinical signs	0.171*

* p = 0.05 level (2-tailed)

Table 5. Explanatory Variables for Thoughts About Cancer at Least Sometimes

Variable	b	SE	Wald	df	p	Odds Ratio	95% Confidence Interval	
							Lower	Upper
Total signs of cancer	0.398	0.138	8.275	1	0.004	1.489	1.135	1.953
Age groups								
18–40 years	–	–	–	–	–	1.000	–	–
41–50 years	1.325	0.521	6.476	1	0.011	3.763	1.356	10.445
51+ years	0.487	0.450	1.170	1	0.279	1.627	0.673	3.931
Mother with breast cancer (n = 135)	–0.208	0.407	0.262	1	0.608	0.812	0.366	1.802
Sisters with breast cancer (n = 79)	0.024	0.051	0.211	1	0.646	1.024	0.926	1.133
Second-degree relatives with breast cancer (n = 143)	0.020	0.162	0.015	1	0.903	1.020	0.743	1.400

N = 200

Fry, Rush, & Steel, 2001; Cunningham et al., 1998; Easterling & Leventhal, 1989; Hopwood et al., 1998; Kash et al., 1995; Lerman et al., 1996; Lloyd et al., 1996). The use of one standard risk-assessment question may not have been sufficient to fully characterize risk perception. This problem has been reported previously (Bish et al., 2002; Cull et al., 2001), and future studies of worry should include more sensitive measures of perceived risk.

Previous research reported that the amount and frequency of symptoms (symptom burden) elicited worry about cancer in known at-risk women who perceived that they were at high risk for cancer. However, the equivalent symptom burden in known high-risk women with perceived low risk of cancer did not elicit worry (Easterling & Leventhal, 1989). These results may help to explain why participants in this study worried “sometimes” when the correlation of perceived risk with worry was nonsignificant and total symptom burden was low.

Only one clinical sign, having a breast biopsy, was correlated significantly with cancer worry. Because of the family history of breast cancer, however, this symptom cue would be expected to reactivate a threat cognition (Easterling & Leventhal, 1989). The positive significant correlation of *total* clinical signs of breast cancer with cancer worry suggests that in high-risk women, a constellation of signs might be more worrisome than occurrence of a single sign or symptom.

Explanatory Variables of Cancer Worry

Women with more clinical breast symptoms were almost 1.5 times more likely to have higher levels of breast cancer worry. This finding was consistent with results of other studies of women at high risk for breast cancer (Audrain et al., 1997; Cunningham et al., 1998). Informed women at high risk, however, may be more likely to report breast symptoms (Cunningham et al.).

Age was related significantly to cancer worry, and women aged 41–50 were almost four times more likely to have high worry than other women. This age group as an explanatory variable for higher worry scores was expected and reflects the prime age when breast cancer could develop in these women (Lynch & Lynch, 1996). Younger women also may be at the age when their mothers or sisters were diagnosed with breast cancer and become concerned that they may develop cancer as well.

Other reports (Baider, Ever-Hadani, & De-Nour, 1999; Kash et al., 1992; Lerman et al., 1991; Lloyd et al., 1996;

McCaul et al., 1998) found a positive relationship between family history and cancer worry; however, in this study, history of breast cancer in first- or second-degree relatives did not predict worry. Although this finding is difficult to explain, perhaps in this particular group of women, family history, as a stimulus instilling an abstract threat cognition, is so omnipresent that worry diminishes over time and moderate worry becomes stable.

Limitations

Although this study adds to the limited knowledge base of symptom-based cancer worry, this research has additional limitations. Concomitant use of other instruments that assess benign breast problems might present a more complete picture of symptoms and can induce worry. Another limitation was the lack of diversity among participants, particularly regarding ethnicity and educational and socioeconomic levels. However, women who participate in this type of research tend to be white, well educated, and financially secure (Cull et al., 2001). Continued investigations of cancer worry in a less homogenous sample of women at high risk for breast cancer will provide a better understanding of the construct.

Research and Clinical Implications

Worry is an important construct because it may play a critical role in how at-risk women view their vulnerability to cancer and what they do to reduce their risk. However, the relationships among cancer worry, perceived risk, and risk-reducing actions still need further clarification in this population. Additional research is needed to better elucidate the role of neutral and cancer-specific symptoms as cues to worry in individuals at hereditary risk for cancer. For example, worry levels in younger high-risk women could be ascertained prior to, at the time of, and after their first clinical symptom of breast cancer. More sensitive instruments need to be developed to assess symptoms in high-risk individuals who have not yet had a diagnosis of cancer. Study of the relationship of symptom-based worry with actual preventive behaviors practiced by high-risk women is a logical next step of this research.

Other studies (Bish et al., 2002; Lerman et al., 1996) found that cancer genetic risk counseling significantly decreased worry. Therefore, nurses should consider including assessments of worry as part of routine data collection for genetic risk counseling. Additionally, by understanding that some lev-

els of worry (e.g., moderate levels) may be beneficial for high-risk women, nurses can reassure those women that being somewhat worried is not detrimental and even may have positive consequences. Nurses also should be aware that women who exhibit extreme distress require appropriate counseling and support.

This study has further implications for cancer genetic risk counseling in that regardless of the extent of their family histories of cancer, women aged 41–50 with one or more clinical symptoms of breast cancer may have high levels of worry. In this regard, routine assessment of worry and clinical breast symptoms in this age group may be prudent.

Results of this study add to the expanding body of knowledge of cancer worry in women with hereditary risk factors for breast cancer. Continued investigation of cancer worry can lead to studies of interventions specifically targeted toward reducing (or increasing) worry to optimal levels in this high-risk group of women.

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