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## Factors associated with breast cancer worry three years after completion of adjuvant treatment

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### Abstract

**OBJECTIVE**—Although many survivors continue to worry about cancer years after completing treatment, little is known about factors associated with cancer worry. This study examined associations between breast cancer worry and demographic and clinical variables, as well as fatigue, symptom burden, and risk perception in a sample of breast cancer survivors three years post-adjuvant treatment. We hypothesized that after controlling for demographic and treatment factors, a significant proportion of variance in cancer worry would be explained by greater fatigue severity, more symptom burden, and greater perceived risk of recurrence.

**METHODS**—Stage 0–II breast cancer patients ( $N = 202$ ) completed measures of risk perception, cancer worry (modified Lerman's Cancer Worry Scale), symptom burden (Memorial Symptom Assessment Scale), and fatigue severity (Fatigue Symptom Inventory) three years after completing adjuvant treatment. Multiple regression analyses were used to determine the proportion of variance in cancer worry accounted for by fatigue, symptom burden, and risk perception after controlling for demographic and clinical variables.

**RESULTS**—Age, fatigue, symptom burden, and risk perception each explained a significant proportion of variance in cancer worry ( $p < .05$ ). Fatigue, symptom burden, and risk perception together accounted for 27% of the variance in cancer worry after controlling for demographic and clinical factors ( $p < .01$ ).

**CONCLUSIONS**—The hypothesis was supported that fatigue, symptom burden, and risk perception are associated with cancer worry among breast cancer survivors. It is possible that lingering fatigue and other symptoms may remind breast cancer survivors of their disease.

### Keywords

breast cancer; worry; fatigue; symptom burden; risk perception; survivorship

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As more people are living longer post-treatment for breast cancer (BC), there is a need to understand the worries of these individuals. Among survivors, cancer worry is broadly

defined as the fear or worry that cancer will return or progress [1]. Worry is distinct from risk perception, as the former relates to an emotional reaction and the latter to a cognitive reaction [2]. Cancer worry is consistently endorsed by survivors as a lingering concern post-treatment [3–7]. One study found that over a third of BC survivors rated worrying about cancer as a dominant concern and nearly half reported unmet needs about addressing these fears [8].

Understanding characteristics associated with cancer worry can help target those who are likely to experience such fears. A model proposed by Deimling and colleagues [3] identified primary stressors (personal and cancer/treatment characteristics) and secondary stressors (current health factors) contributing to cancer worry. Regarding personal characteristics, younger age has been consistently related to greater cancer worry [1, 3–5, 7, 9–11]. Research has also shown evidence for ethnic differences in reported cancer worry, with African Americans reporting lower levels of worry than white women [3, 10] and Hispanic women who are low in acculturation reporting higher levels [10]. Lower education has been related to greater cancer worry in at least one study [12], but not others [1, 9].

Regarding cancer/treatment characteristics, studies have found relationships between cancer worry and more advanced disease among those with early-stage cancer [9, 13]. Research has also demonstrated associations between past mastectomy [13], radiation [3, 10], and chemotherapy [4] and greater cancer worry.

Greater perceived risk of cancer recurrence has been related to greater cancer worry in BC survivors [9], though a study of colorectal cancer survivors found that long-term survivors (defined as having completed treatment more than 41 months prior) had significantly lower perceived risk than short term survivors [11]. Post-treatment symptoms have also been associated with cancer-related worry [3, 12]. Regarding fatigue, a recent study found associations between cancer worry and fatigue while on treatment [10]. However, a study of long-term survivors of testicular cancer found that correlations between cancer worry and fatigue were no longer significant in multivariate analyses [12]. Thus, more work is needed to understand the relationship between cancer worry and post-treatment fatigue, which may serve as a trigger of cancer-related thoughts and worries among survivors.

The aim of the current study was to investigate associations among cancer worry and demographic and treatment variables, and secondary stressors (i.e., fatigue, symptom burden, and risk perception) three years after completion of adjuvant treatment for BC. We hypothesized after controlling for demographic and treatment variables, a significant proportion of variance in cancer worry would be explained by greater fatigue severity, more symptom burden, and greater risk perception.

## Methods

### Patients and procedure

Data were drawn from a larger study at two major cancer centers that aimed to determine the severity, course, and predictors of fatigue in women with early-stage BC over the first 3 years following completion of active treatment [14, 15]. Patients scheduled for adjuvant therapy were recruited from Moffitt Cancer Center in Tampa, FL and Markey Cancer Center in Lexington, KY. Initial eligibility criteria were: Stage 0–II BC, scheduled to receive adjuvant therapy, no history of cancer (besides basal cell skin carcinoma), no prior history of adjuvant therapy, 18 years old, fluent English, and no other conditions for which fatigue is a prominent symptom (e.g., AIDS, fibromyalgia, multiple sclerosis). Criteria for the three year follow-up were: no disease recurrence or new cancer diagnosis. Institutional Review Board approval was received and participants provided informed consent.

The focus of this report is on data collected at three years post-treatment. Of the 232 participants who completed follow-up, 23 were missing cancer worry data and 7 were missing additional data. Analyses are based on participants with complete data ( $N=202$ ).

## Mesures

Demographic characteristics were assessed via self-report. Clinical characteristics were assessed via medical record review.

*BC worry* was assessed by averaging responses to a four-item scale adapted from Lerman's Cancer Worry Scale [16]. Participants were asked, to rate for the past month, 1) "How often have you been concerned about getting breast cancer again?" 2) "How often have you thought about your own chances of having breast cancer again?" 3) "How often have thoughts about breast cancer affected your mood?" and 4) "How often have thoughts about breast cancer affected your ability to perform your daily activities?" (1=not at all or rarely, 2=sometimes, 3=often, 4=a lot;  $\alpha=0.77$ ).

*Risk perception* was assessed using two questions [9]: 1) "How likely do you think you are to have breast cancer again during your lifetime?" (1=extremely unlikely, 6=extremely likely) and 2) "What do you think your chances are of having breast cancer again in your lifetime compared to other women your age who have received the same treatment for the same type of breast cancer?" (1=much higher, 5=much lower). A composite score for the two items was created by reverse scoring the second item so that higher scores indicated greater perceived risk, calculating z-scores for both items because they used different scales, and summing the z-scores [17]. The two items were positively correlated ( $r=.44$ ,  $p<.01$ ).

*Fatigue* was assessed using the fatigue severity subscale of the Fatigue Symptom Inventory [18]. The fatigue severity score was obtained by averaging four items assessing most, least, and average fatigue in the past week and current fatigue (0=not at all fatigued, 10=as fatigued as I could be;  $\alpha=0.92$ ).

*Symptom burden* was assessed using 26 symptoms included on the Memorial Symptom Assessment Scale [19]. For the current analyses, the item assessing fatigue was removed. The number of symptoms experienced by patients in the past week was summed for a total score. Higher scores indicate greater symptom burden.

## Statistical Analyses

Pearson correlations were performed between BC worry and the other study variables. Hierarchical linear regression analyses were conducted to identify the separate and combined variance in BC worry accounted for by demographic and clinical variables, as well as fatigue, symptom burden, and risk perception.

## Results

Descriptive statistics can be found in Table 1. Participants ( $M=57$  years old, range 33–82) were diagnosed with Stage 0 (12%), I (53%) or II (35%) disease and received chemotherapy (9%), radiotherapy (52%) or both (39%). Thirteen percent received a mastectomy and 60% received hormone therapy. Most were Caucasian (90%) and approximately half were college graduates (47%).

Two-thirds of participants had an average BC worry score between 1.25 and 2.75, suggesting a moderate level of worry. Greater BC worry was associated with younger age ( $r=-.18$ ,  $p<.01$ ), chemotherapy ( $r=.09$ ,  $p<.01$ ), more fatigue ( $r=.35$ ,  $p<.01$ ), greater perceived risk ( $r=.38$ ,  $p<.001$ ), and greater symptom burden ( $r=.43$ ,  $p<.01$ ). Cancer

worry was not associated with education, race, hormone therapy, mastectomy, or disease stage ( $p$ -values  $> .05$ ).

Because disease stage and treatment type were highly correlated ( $r = -.64$ ,  $p < .01$ ), only treatment type was included in the regression analyses (see Table 2). In step 1, demographic factors accounted for 4% of the variance in BC worry ( $p = .05$ ). Of the three, only age was statistically significant; younger age was associated with more worry ( $p < .01$ ). In step 2, clinical factors did not significantly contribute to variance in BC worry ( $p = .18$ ). In step 3, fatigue, symptom burden, and risk perception each explained a significant proportion of variance in BC worry; together they accounted for 27% of the remaining variance ( $p < .01$ ). Overall, demographic and clinical variables, and fatigue, symptom burden, and risk perception accounted for 33% of the variance in BC worry.

## Discussion

Greater BC worry three years after completing adjuvant treatment for BC was associated with younger age, having received chemotherapy, more severe fatigue, greater symptom burden, and greater perceived risk of recurrence. Controlling for demographic and clinical factors, fatigue, symptom burden, and risk perception each explained a significant proportion of variance in BC worry.

The finding that younger age was associated with greater BC worry is consistent with prior literature [1, 3–5, 9, 10]. Although we did not find associations between BC worry and race, this may be due to the small percentage of racial minorities. Of particular interest were the significant effects for risk perception, fatigue, and symptom burden. It is logical that those who *perceive* themselves at greater risk for recurrence (which may not correspond to actual risk) worry more. The finding that these two constructs are positively related, but not strongly correlated is consistent with prior literature on worry and risk perception [2].

A recent study found a relationship between BC worry and symptom management and fatigue and while on treatment [10]. A study of long-term cancer survivors found a significant relationship between current symptoms and cancer worry, but that study did not include a measure of fatigue [3]. However, a study of long-term testicular cancer survivors that assessed both symptoms and fatigue found non-significant relationships between these variables and cancer worry when they were included in a multivariate analysis [12]. The current study adds to the literature by demonstrating that three years post-treatment for BC, current fatigue, symptoms, and risk perceptions each contribute a unique proportion of the variance in cancer worry after controlling for demographic and treatment variables. It is possible that lingering fatigue and symptoms may serve as a reminder of the disease, which leads to more worry.

Understanding factors associated with BC worry is important, as worry may be associated with health behaviors [17, 20]. While some worry may lead to healthy behaviors, too much or too little may lead to harmful behaviors. A population-based study found women with moderate levels of worry were more likely to undergo annual mammography than those with mild or severe levels of cancer worry [20]. In the current study, two-thirds of participants had a moderate level of worry. We previously reported that BC survivors who experience greater BC worry were less likely to avoid tobacco use [17]. However, a study of colorectal cancer survivors found that greater risk perceptions and worry were associated with a greater intention to change health behaviors, but only intrusive thoughts were related to actual behavior change [11]. More work is needed to understand how cancer worry may be related to a variety of cancer risk reduction behaviors among cancer survivors.

Limitations include the sample's homogeneity (mostly white, early-stage BC survivors), which precludes generalizations to more diverse populations or people with advanced disease. Furthermore, we did not include a measure of co-morbid medical conditions; however patients with medical conditions for which fatigue was a prominent symptom were excluded.

Clinicians should be aware that, three years after completing adjuvant treatment, BC survivors who report experiencing fatigue and other symptoms may also be experiencing greater cancer worry than those who report less residual symptoms. Consideration should be given to referring survivors experiencing heightened worry to a mental health professional.

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**Table 1**

## Descriptive statistics

	<b>M</b>	<b>SD</b>	<b>Minimum</b>	<b>Maximum</b>
Cancer worry	1.50	0.53	1.00	3.75
Fatigue	56.76	11.95	22.00	83.00
Symptom burden	5.68	4.10	0.00	22.00
General risk perception	3.17	1.16	1.00	6.00
Comparative risk	3.10	0.81	1.00	5.00
Age (years)	57.75	9.25	33.17	82.51
Time since diagnosis (years)	4.08	0.30	2.56	5.15

  

	<b>N</b>	<b>Percentage</b>
Race		
White	181	89.60
Non-White	21	10.40
Education		
College graduate	94	40.10
Not college graduate	108	53.47
Stage		
0	25	12.38
I	107	52.97
II	70	34.65
Treatment		
Chemotherapy	17	8.42
Radiotherapy	106	52.48
Both	79	39.11
Surgery type		
Lumpectomy	176	87.13
Mastectomy	16	7.92
Both	4	1.98
Bilateral mastectomy	6	2.97
Hormone therapy		
Yes	121	59.9
No	81	40.10
Menopausal status		
Premenopausal	31	15.35
Postmenopausal	171	84.65

Table 2

Hierarchical regression analysis of cancer worry<sup>a</sup>

Step and predictor	Statistics by step		Statistics by predictor		Final model	
	R <sup>2</sup>	Δ R <sup>2</sup>	β	t	β	t
Step 1: Personal characteristics	.04	.04 <sup>*</sup>				
Age			-.19	-2.71 <sup>**</sup>	-.12	-1.87
College graduate <sup>b</sup>			-.06	-0.81	-.02	-0.33
Race <sup>c</sup>			-.03	-0.48	-.03	-0.42
Step 2: Treatment factors	.06	.02				
Chemotherapy <sup>d</sup>			.14	1.86	-.08	-1.26
Hormone therapy <sup>b</sup>			.07	1.03	-.01	-0.10
Mastectomy <sup>b</sup>			.02	0.30	.04	0.69
Step 3: Current status	.33	.27 <sup>**</sup>				
Fatigue			.15	2.03 <sup>*</sup>	.15	2.03 <sup>*</sup>
Symptom burden			.28	3.70 <sup>**</sup>	.28	3.70 <sup>**</sup>
Risk perception			.30	4.83 <sup>**</sup>	.30	4.83 <sup>**</sup>

 $R^2$ =squared multiple correlation; β=standardized beta weight.<sup>a</sup> Criterion is the four-item modified Cancer Worry Scale. Analyses were also ran with the first two items from this scale removed; the pattern of results were the same with the exception that in the final model the effect of age was also significant ( $p < .05$ ).<sup>b</sup> 0=No, 1=Yes.<sup>c</sup> 0=Non-Caucasian, 1=Caucasian.<sup>d</sup> 0=Radiotherapy only, 1=Chemotherapy or Chemotherapy plus Radiotherapy\*  $p < .05$ \*\*  $p < .01$