# Correlates of Worry About Recurrence in a Multiethnic Population-Based Sample of Women With Breast Cancer

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BACKGROUND: Worry about recurrence (worry) is a persistent concern of breast cancer survivors. Little is known about whether race/ethnicity or healthcare experiences are associated with worry. METHODS: Women with nonmetastatic breast cancer diagnosed from June 2005 to February 2007 and reported to Detroit or Los Angeles Surveillance, Epidemiology, and End Results registries were surveyed (mean 9 months postdiagnosis); 2290 responded (73%). Latinas and African Americans were oversampled. A worry scale was constructed as the mean score of 3 items (on 5-point Likert, higher = more worry): worry about cancer returning to the same breast, occurring in the other breast, or spreading to other parts of the body. Race/ethnicity categories were white, African American, and Latina (categorized into low vs high acculturation). The worry scale was regressed on sociodemographics, clinical/treatment, and healthcare experience factors (eg, care coordination collapsed into low, medium, high). RESULTS: Low acculturated Latinas reported more worry and African Americans less worry than whites (P < .001). Other factors independently associated with more worry were younger age, being employed, more pain and fatigue, and radiation (Ps < .05). With all factors in the model, less worry was associated (all Ps < .05) with greater ease of understanding information (2.89, 2.99, 2.81 for low, medium, high), better symptom management (3.19, 2.89, 2.87 for low, medium, high), and more coordinated care (3.36, 2.94, 2.82 for low, medium, high). Race/ethnicity remained significant controlling for all factors (P < .001). CONCLUSIONS: Less acculturated Latina breast cancer patients are vulnerable to high levels of worry. Interventions that improve information exchange, symptom management, and coordinating care hold promise in reducing worry. Cancer 2011;117:1827-36. © 2011 American Cancer Society.

KEYWORDS: breast cancer, recurrence, quality of life, minority health, health status disparities, quality of healthcare.

**Because** of advances in early detection and treatment, most women with early stage breast cancer face an optimistic future. As more women survive breast cancer, interest has increased regarding quality of life (QOL) issues in survivorship. The transition between active treatment and early survivorship is a vulnerable point in recovery, with the quality of adjustment affecting future well-being of survivors. Survivors consistently rank worry about recurrence (hereafter referred to as *worry*) among their most pressing concerns, <sup>1-3</sup> and one that persists well into survivorship. <sup>2,4-7</sup>

Helping survivors understand and manage their worry is a priority identified by the Institute of Medicine (IOM). Greater focus on worry is essential given the documented impact worry has on treatment decision making, surveillance behaviors, and QOL. Women who have more concerns about recurrence are more likely to choose mastectomy. and get bilateral versus single mastectomy. Increased worry can deter women from seeking appropriate follow-up care or may encourage maladaptive behaviors such as excessive checking. Several studies have shown that high levels of worry can lead to depression, anxiety, and decreased QOL. 2,7,14-16

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Many studies have shown that worry varies by sociodemographic factors<sup>5,14,17,18</sup>; however, most prior studies have been limited by small, clinic-based samples, using inconsistent measures. A major gap in knowledge is whether worry differs across racial/ethnic groups, including Latinos. Although Latinos are a racially and socioculturally heterogeneous population, 19 cultural commonalities exist, including shared language, health beliefs, and healthcare system experiences that impact health and QOL outcomes.<sup>20</sup> Two studies report that Latinas have more worry than other groups, 15,17 but these studies do not consider the role of acculturation. When acculturation has been measured across other health outcomes, Latinas with low acculturation experience more delay, 10 lower decision satisfaction, 9 and greater difficulty with physician-patient communication.<sup>21</sup>

The association between clinical/treatment factors and worry also needs to be further explored. Some studies suggest more comorbidities and symptoms contribute to greater worry, 7,22 whereas others have found that receiving chemotherapy may be associated with worry. 3,14,23 Finally, few studies have examined factors in the healthcare experience (eg, care coordination) that might elucidate differences in worry across vulnerable subgroups. Negotiating the healthcare system remains an understudied element of acculturation. 24 By better understanding the influence of cultural adaptation on health and disease, modifiable factors can be identified, high-risk populations targeted, and interventions tailored to specific components affecting risk. 24

To address these gaps in the literature, we used a large multiethnic population-based sample of women with breast cancer to examine the following questions.

- 1) What are the sociodemographic, clinical, and treatment correlates of reported worry about recurrence as women transition into breast cancer survivorship?
- 2) Is patients' appraisal of their healthcare experience associated with worry about recurrence, and does it mediate the relationship between worry and sociodemographic, clinical, and treatment factors?
- 3) Are sociodemographic correlates of worry about recurrence modified by factors related to the healthcare experience?

# MATERIALS AND METHODS

### Study Population

Between June 2005 and February 2007, 3252 women aged 20 to 79 years diagnosed with primary ductal carci-

noma in situ or invasive breast cancer stages I, II, or III<sup>25</sup> in Los Angeles (LA) and Detroit were selected for the study. Of these women, 119 were excluded because: 1) the physician did not want the patient contacted (n = 20), 2) the woman did not speak English or Spanish (n = 17), 3) the woman was too ill or incompetent to participate (n = 59), or 4) the woman denied having cancer (n = 23). Of 3133 eligible women included in the final sample, 432 (13.8%) could not be located, and 411 (13.1%) were contacted but did not return a survey. Thus, 2290 patients returned a survey (73.1% response rate). The mean time from diagnosis to survey completion was 9.2 months. Of the women who completed the survey, 22 could not be merged with the Surveillance, Epidemiology, and End Results (SEER) program registries data, leaving an analytic sample of 2268 (72.1% of eligible patients). Compared with respondents, nonrespondents were more likely to be African American (34.9% vs 26.2%, P < .001), be unmarried (23.0% vs 19.3%, P = .01), and have stage II or III disease (43.4% vs 40.5%, P = .005), and less likely to receive lumpectomy (54.5% vs 63.2%, P = .02).

# Population Sampling and Data Collection

Eligible breast cancer patients were accrued via rapid case ascertainment as they were reported to the LA Cancer Surveillance Program and the Metropolitan Detroit Cancer Surveillance System. All African American women were selected on demographic information from the treating hospitals. Latina women in LA were selected by including all women designated as Hispanic by the hospital, as well as all women whose surname indicated a high probability of being Latina, based on a list generated from the 1980 US Census. A random sample of the remaining white patients in LA and Detroit were selected to reach the targeted accrual number. Asian women in LA were excluded because they were enrolled in other studies.

Physicians were notified of our intent to contact their patients. If no objection was received, the patients were mailed an introductory letter, survey materials, and a \$10 cash gift. Women from LA likely to be Latina based on the US Spanish Surname list were sent both English and Spanish materials. The Spanish survey was not used in Detroit because few Hispanic women (~50) were diagnosed with breast cancer and reported to the SEER registry during the study. The Dillman survey method was used to encourage survey response. The study protocol was approved by the institutional review boards of the University of Michigan, University of Southern California, and Wayne State University.

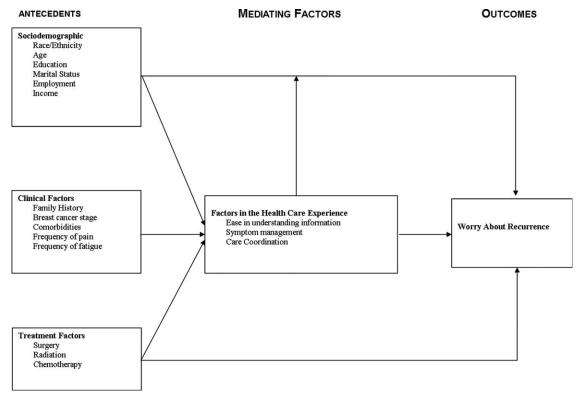


Figure 1. A modified stress appraisal conceptual model for understanding worry about recurrence is shown.

# Survey Measures

The questionnaire was developed based on prior research in the target population. <sup>9,10,23</sup> Extensive piloting was done with both English and Spanish versions. The Spanish survey was developed using rigorous translation approaches including forward/back techniques to ensure congruency between surveys. Internal consistency tests were used to assess reliability of measures.

A modified stress/appraisal theoretical framework<sup>28,29</sup> adapted from Lazarus<sup>28</sup> and used by Northouse et al<sup>29</sup> guided our survey (Fig. 1). According to the framework, there are antecedent variables (eg, person, illness related) and mediating variables (eg, appraisal factors) that directly or indirectly affect QOL. We identified antecedent variables (categorized into person and clinical/treatment factors) and mediating factors (appraisal of healthcare experience) potentially affecting worry.

# Dependent Variable

Worry about recurrence was assessed with 3 items regarding worry about cancer: 1) coming back in the same breast, 2) occurring in the other breast, and 3) spreading to other parts of the body. The 5-point Likert response

scale for each item ranged from "not at all" to "very much," with good internal consistency (Cronbach alpha = .88). We created an overall worry about recurrence score as the mean across items (higher scores indicate more worry; range 1-5).

# Independent Variables

### Antecedent factors

Survey information on race and ethnicity was combined to create the race/ethnicity variable. Women indicated their race (white, black/African American, American Indian or Alaska Native, Asian or Pacific Islander, or other) and whether they were Hispanic/Latina (yes/no). The Short Acculturation Scale for Hispanics, developed by Marin and colleagues, <sup>30</sup> is a widely used, reliable, and valid measure to identify level of acculturation. <sup>31,32</sup> The 4 items in the Short Acculturation Scale for Hispanics indicate preference for English or Spanish in different contexts (usually read/speak, think, use at home, use with friends) on a 5-point scale ("English only" to "Spanish only"). We aggregated across items to calculate a mean score. Fifty-five percent of Latina patients scored  $\leq$ 4 on the 5-point scale (strongly preferring Spanish

across contexts). Race/ethnicity was thus divided into 4 categories (white, African American, Latinas-high acculturation [Latinas-high], and Latinas-low acculturation [Latinas-low]). Compared with Latinas-high, Latinas-low were much more likely to be foreign born (99.4% vs 35.2%). Additional demographic variables were age at diagnosis (<50, 50-70, >70 years), education (<high school [HS], HS diploma, >HS diploma), employment status (yes/no), marital status (currently married/ partnered, divorced/widowed/separated, never married), and income (<\$20,000, \$20,000-\$69,999, \$70,000+, unknown).

Clinical factors included family history of breast cancer (first degree, no first degree) number of comorbidities (0, 1, 2 or more), frequency of symptoms during treatment (pain and fatigue on a 5-point Likert scale, "not at all" to "very much"), and stage at diagnosis (0, I, II/III). Breast cancer stage was obtained via SEER data using the American Joint Committee on Cancer criteria. <sup>25</sup> Treatment factors included surgical procedure (lumpectomy or mastectomy), radiation therapy (yes/no), and chemotherapy (yes/no).

### **Mediating factors**

The patients' appraisal of their healthcare experience was measured across 3 factors: 1) ease of understanding information, 2) symptom management, and 3) care coordination. Ease of understanding information was measured as the mean response to 2 items (5-point Likert scale, from never to always): 1) "How often did you have problems understanding information about your breast cancer and its treatment because of difficulty with written information?" and 2) 'How often did you have someone (like a family member, hospital/clinic worker, or caregiver) help you read written information from the hospital or clinic?" This scale ranged from 1 to 5, with a mean of 4.32, and Cronbach alpha of .652. Symptom management was the response to the question, "Do you think your doctor(s) and their staff did everything they could to help you manage your symptoms" (5-point Likert scale from "not at all" to "very much"). This measure ranged from 1 to 5, with a mean of 4.06. The care coordination items were based on the Agency for Healthcare Research and Quality<sup>33</sup> report and other cancer quality of care literature.<sup>34</sup> The measure was the mean response to 5 items (5-point Likert scale, never to always): 1) how often patients received help from their surgeons with referrals to other physicians,<sup>2</sup> 2) how often they knew whom to ask when they had questions, 3) how often they were given confusing advice (reverse coded), 4) how often they knew what the next step in their treatment was, and 5) how often their physicians had the medical information they needed. The care coordination scale ranged from 1 to 5, with a mean of 4.50 and Cronbach alpha of .697. Higher scores for all 3 healthcare experience measures indicate more understanding of information, better symptom management, and better coordination of care. Multi-item scale scores were calculated by averaging items. Each healthcare experience measure was collapsed into 3 ordinal categories (low, medium, high) to optimize the clarity of presentation. Other specifications of these variables (eg, interval scale) yielded similar results.

# Analysis Plan

Of the 2268 available for analysis, we omitted 431 (19.4%) women with missing values for any variable in the analyses; thus, the final analytic sample included 1837 women. Sample weights were included to adjust for design effects resulting from differential selection by race/ ethnicity and nonresponse. Descriptive statistics were used to characterize the distribution of study covariates overall and by mean worry score. Bivariate associations were investigated between worry and sociodemographics, clinical/treatment, and healthcare system factors. We also tested bivariate associations between sociodemographics and factors within the healthcare experience, an important step is assessing mediation. Multivariate regression models investigated associations in a sequential modeling by including sociodemographics and clinical/treatment factors in Model 1, and then adding the potential mediating factors related to the healthcare experience in Model 2 (Research Question 2). All 2-way interactions between sociodemographics and healthcare experience factors were examined testing a moderating role (Research Question 3). All analyses were performed using SAS V9 programming (SAS Institute, Cary, NC).

### RESULTS

Table 1 displays the sample characteristics overall and by mean worry scores. The mean age was 56.8 years (standard deviation = 11.4), and 68.7%, 14.3%, 8.1%, and 8.9% were white, African American, Latinas-high, and Latinas-low, respectively. In bivariate analyses, there were significant differences in mean worry scores (all *P* values <.001) for all sociodemographic variables except level of income.

 Table 1. Sample Characteristics Overall, and by Mean Worry About Recurrence

	Overall		Mean Worry	P
	N	% <sup>a</sup>	About Recurrence Score (range 1-5)	
Sociodemographic				
Race/Ethnicity				<.001
White	870	68.7	2.74	
Black	478	14.3	2.47	
Latina (High acculturation)	233	8.1	3.08	
Latina (Low acculturation)	256	8.9	3.78	
Age	200	0.0	5 5	<.001
<50	526	25.8	3.17	ζ.σσ.
50-70	1064	59.6	2.81	
>70	247	114.6	2.27	
Education	2.7	111.0	2.21	<.001
<high diploma<="" school="" td=""><td>331</td><td>12.7</td><td>3.23</td><td>&lt;.001</td></high>	331	12.7	3.23	<.001
High school diploma	374	19.3	2.86	
>High school diploma	1132	68.0	2.73	
Employed	1102	00.0	2.70	<.001
Yes	1061	58.6	2.92	<.001
No	776	41.4	2.68	
	770	41.4	2.00	.004
Marital status	1049	60.6	2.89	.004
Married/partner				
Unmarried	788	39.4	2.72	074
Income, \$	007	40.5	0.00	.274
<20,000	327	13.5	2.92	
20,000- 69,999	677	36.4	2.84	
≥70,000	505	32.4	2.75	
Missing	328	17.7	2.83	
Clinical Factors				
Family history				.282
First degree relative	342	19.4	2.76	
No first degree relative	1495	80.6	2.84	
Breast cancer stage				.007
0	352	19.5	2.66	
Ī	690	40.0	2.81	
/	795	40.5	2.91	
Number of co-morbidities		10.0	2.01	.024
None	749	42.2	2.91	.02 1
One	540	30.7	2.74	
Two or more	548	27.1	2.77	
Frequency of Pain	040	21.1	2.11	<.001
None/A little	1029	56.5	2.55	\.001
Some	592	32.0	3.11	
	216	11.5	3.32	
Quite a bit/very much	210	11.5	3.32	<.001
Frequency of Fatigue	400	OF G	0.40	<.001
None/A little	498	25.6	2.43	
Some	360	18.6	2.65	
Quite a bit/very much	979	55.8	3.05	
Treatment Factors				
Surgical Procedure				.048
Lumpectomy	1335	74.5	2.85	
Mastectomy	502	25.5	2.72	
Radiation therapy				<.001
Yes	1307	70.7	2.93	
No	530	29.3	2.57	
Chemotherapy		_3.0		<.001
Yes	954	47.6	2.97	(.551
No	883	52.4	2.68	

<sup>&</sup>lt;sup>a</sup> Weighted percentage.

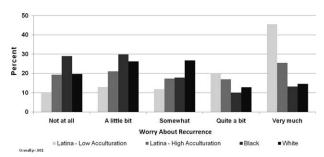


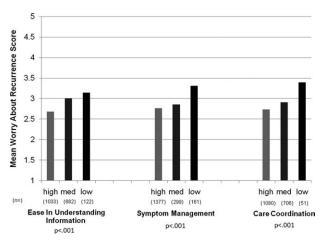
Figure 2. Percentage of women reporting various levels of worry about recurrence is shown by race/ethnicity.

Women who were younger, Latina, employed, married, and less educated had higher levels of worry. More worry was also reported by women with higher cancer stage, fewer comorbidities, and more frequent pain and fatigue during treatment (all Ps < .05). Women who had lumpectomy compared with mastectomy reported more worry, as did women who received radiation and/or chemotherapy (all Ps < .05).

For the total sample, item mean levels of worry were distributed as follows: 14% "not at all," 32% "a little bit," 25% "somewhat," 16% "quite a bit," and 14% "very much." Figure 2 shows the percentage of women reporting levels of worry by race/ethnicity. Almost 29% of African American women expressed low levels of worry (corresponding to "not at all"), compared with about 10%, 19%, and 20% for Latinas-low, Latinas-high, and whites, respectively. Alternatively, almost 46% of Latinas-low reported the highest category of worry ("very much") compared with 25%, 13%, and 14% for Latinas-high, African American, and white women, respectively.

Figure 3 displays unadjusted mean worry scores for the 3 healthcare experience factors. Greater ease in understanding information (3.14, 3.01, 2.68 for low, medium, and high, P < .001), better symptom management (3.31, 2.85, 2.76 for low, medium, and high, P = .001), and more coordinated care (3.39, 2.91, 2.73, for low, medium, and high, P < .001) were all significantly associated with lower levels of worry.

In the multivariate findings (Table 2), where Model 1 adjusted for sociodemographic and clinical/treatment factors, worry scores were significantly associated with race/ethnicity, age, employment status, frequency of pain and fatigue, and receipt of radiation therapy (all *Ps* < .05). More worry was reported by Latinas (low and high) than whites, and women who were younger, were employed, had more comorbidities, had more pain and fatigue, and who received radiation. In Model 2, which further adjusted for the 3 factors from the healthcare experience, associations were only slightly reduced for sociode-



**Figure 3.** Factors within the healthcare experience are shown by worry about recurrence score (unadjusted).

mographic, clinical, and treatment factors, with the exception of the number of comorbidities, where the associations were reduced and no longer significant (P =.091). In this model, Latinas-low reported more worry than other groups, with a worry score of 3.80 versus 3.17, 2.59, and 2.90 for Latinas-high, African Americans, and whites (P < .001). Although worry continued to be significantly higher for Latinas-high than whites, the magnitude of the differences were small, suggesting differences may be a result of a large sample. African American women reported significantly less worry than whites. Model 2 also demonstrates associations between worry scores and patients' appraisal of their care experiences. Specifically, less worry was associated with greater ease of understanding information (P = .047), better management of symptoms (P = .044), and more coordinated care (P = .012). We did not find any significant interactions between sociodemographics and healthcare experience factors, suggesting that sociodemographic factors and worry scores were not modified by healthcare experience factors.

# DISCUSSION

In this diverse population-based sample of newly diagnosed breast cancer patients, race, ethnicity, and acculturation were associated with differences in worry about recurrence after controlling for other sociodemographic, clinical/treatment, and healthcare experience factors. Latinas-low reported substantially more worry than white women. Indeed, the mean difference was the largest observed in the study (nearly 1 point in the 5-point range). Several clinical studies with smaller samples reported that Latinas are more likely to express worry and

**Table 2.** Adjusted Mean Difference in Worry About Recurrence by Sociodemographic, Clinical, and Treatment Factors, and Factors in the Health Care Experience

	Model 1	P	Model 2	P
Sociodemographic				
Race/ethnicity		<.001		<.001
Latina (low acculturation)	.907ª		.862ª	
Latina (high acculturation)	.272 <sup>a</sup>		.250ª	
African American	311 <sup>a</sup>		313 <sup>a</sup>	
White	-		-	
Age		<.001		<.001
<50	-		-	
50-70	364 <sup>a</sup>		340 <sup>a</sup>	
>70	772 <sup>a</sup>		745 <sup>a</sup>	
Education		.115		.183
<high diploma<="" school="" td=""><td>-</td><td></td><td>-</td><td></td></high>	-		-	
High schooldiploma	.084		.080	
>High schooldiploma	060		048	
Marital status	.000	.073	.010	.079
Married/partner	.106	.010	.104	.070
Not Married	-		-	
Employed (yes)	.132ª	.028	.120ª	.045
Income, \$	.132	.096	.120	.116
<20,000		.090		.110
•	.044		.066	
20,000-69,999				
≥70,000	126		096	
Missing	.002		.019	
Clinical Factors				
Family history		.992		.941
First degree relative	001		.005	
Breast cancer stage		.449		.451
0	-		-	
İ	.051		.084	
11/111	.115		.105	
Number of co-morbidities		.044		.091
None	-		_	
One	.007		.010	
Two or more	.161 <sup>a</sup>		.143	
Frequency of Pain		<.001		<.001
None/a little	_		_	
Some	.333 <sup>a</sup>		.321 <sup>a</sup>	
Quite a bit/very Much	.487 <sup>a</sup>		.477 <sup>a</sup>	
Frequency of Fatigue	. 101	<.001		<.001
None/a little	_	<.001	_	\.001
Some	.126		.122	
	.398 <sup>a</sup>		.388 <sup>a</sup>	
Quite a bit/very Much	.590		.300	
Treatment Factors				
Surgical Procedure		.120		.100
Lumpectomy	-		-	
Mastectomy	108		113	
Radiation therapy (yes)	.285 <sup>a</sup>	<.001	.290 <sup>a</sup>	<.001
Chemotherapy (yes)	031	.657	113	
Factors in the Health Care Experience				0.47
Ease in understanding information				.047
High			-	
Medium			.135 <sup>a</sup>	
Low			.009	
Symptom management				.029
High			-	
Medium			033	
Low			.244 <sup>a</sup>	
Care coordination				.015
High			-	
			.106ª	
Medium			.100	

 $<sup>^{\</sup>rm a}{\it P} \le$  .05 for the pair-wise comparison.

more emotional distress,<sup>15,17</sup> but to our knowledge no previous study has examined worry by level of acculturation. In contrast, African American women reported lower levels of worry, lending support to the growing literature indicating that African American women report fewer concerns in the early survivorship period<sup>17</sup> and have higher emotional well-being than whites.<sup>35</sup>

Consistent with previous studies, we found that younger women reported substantively more worry. <sup>5,14,17,23,36,37</sup> Younger women likely have fewer peers with serious illness and find cancer more stressful, having fewer coping resources. <sup>14</sup> Whereas education did not remain significant in the full model, being employed was associated with more worry. Women who are employed may worry more because of the consequences of a recurrence on job stability.

Persistent pain and/or fatigue over the treatment period were strongly associated with more worry at survey completion. Possible explanations for this finding include that the symptoms persisted and triggered greater worry,<sup>38</sup> women had a heightened attentional focus on bodily sensations resulting in greater worry (ie, somatoform amplification),<sup>39</sup> and/or women who were anxious reported more symptoms. 40 In addition, the presence of comorbidities may make it more difficult to interpret whether symptoms are because of cancer, resulting in higher worry. Cancer stage was not independently associated with more worry, consistent with many other studies. 3,14,22,41 Current health state may be a more powerful determinant of worry than actual prognosis. Similar to prior studies, we found that receipt of adjuvant therapy on subsequent worry was inconsistent. 3,14,22 Women who received radiation reported more worry, whereas in the final model receipt of chemotherapy did not remain significant. Vickberg<sup>3</sup> reasons that because younger women report more fear and are more likely to receive chemotherapy, chemotherapy is not significant when age is in the model. The impact of aggressive treatment on worry may vary depending on whether the treatment course is viewed as signaling more serious disease or as protection against recurrence. Radiation may have remained significant because skin reactions may still have been present for women receiving radiotherapy, serving as a reminder of their diagnosis and treatment.

This study explored whether women's appraisal of their care experiences was associated with worry. Previous studies suggest women are frequently dissatisfied with information they receive regarding recurrence<sup>12</sup> and generally desire more risk information.<sup>42</sup> Our study and those of others<sup>21</sup> support that difficulty understanding informa-

tion and establishing a good relationship with their physician could contribute to greater worry. Although the presence of symptoms during treatment was associated with more worry later, women who perceived their symptoms were well managed reported less worry. Additional attention to symptom management by providers could be included in survivorship care plans and monitored at follow-up. The challenge is to ensure women's awareness of signs of recurrence while not increasing anxious preoccupation with excessive worry. The IOM report on cancer survivors recommends patients receive a comprehensive care summary and follow-up plan to inform and coordinate delivery of care, which may lead to reduced worry, as supported by our findings.

Factors not measured in this study may explain why racial/ethnic differences in worry persisted after healthcare system experiences were assessed. Culture could impact communication styles and/or perceptions of worry. For African American women it may be culturally appropriate to present a strong image, thereby reporting less worry, whereas for Latinas it may be culturally appropriate to express concerns and greater distress. 17 Low acculturated Latinas may perceive a higher likelihood of recurrence, perceive the impact of a recurrence as more grave, or have greater concerns about the consequences of a recurrence.<sup>3</sup> Even controlling for insurance, education, and income, racial/ethnic differences persisted, with Latinas-low reporting more worry. Finally, cultural variations in coping may contribute to differences in worry. African American breast cancer survivors report more social support 18 and use more religious-oriented coping<sup>17</sup> than whites, whereas low acculturated Latinas report the lowest level of social support. 37,42

Study findings are limited by the cross-sectional design that did not allow for examination of worry over time. Multiethnic longitudinal evaluations of worry are needed to inform effective interventions to reduce disparities. It should be noted that our measure did not assess the duration, frequency, and impact of distress on impairment. Although the validity of attitudes measures are difficult to fully evaluate, the worry measure was positively correlated with more symptoms during treatment, and correlated with our QOL measure (FACT-B) subscales as follows: physical well-being scale, r = -0.313 (P < .001); emotional well-being scale, r = -0.577 (P < .001) (unpublished).

Our study measures were self-reported and may be subject to recall bias because of the time delay from treatment to survey completion. However, we made considerable effort to address response bias through a rigorous

translation process and pilot testing. Our previous publications have also supported the marked differences between Latinas-low versus other groups across a broad array of outcomes. 9,10,35 Nevertheless, ethnicity and acculturation cannot be fully untangled because our acculturation measure was language based and only assessed in Latinas. A major study strength was the large population-based sample with sufficient numbers of Latinas (predominately from Mexico and Central America) to examine the relevance of acculturation. Nevertheless, the US Hispanic population is diverse, and it is not appropriate to generalize our findings to Latinas from other cultural backgrounds.

### **Implications**

Future research is needed to determine from whom, and under what circumstances, cancer patients are receiving risk information. We need to understand providers' perceptions about their responsibilities in informing and addressing patients' worries about recurrence. Validation of women's appraisal of the healthcare experience with the actual receipt of services is an important area for future research. Some of the mean differences we observed in worry between groups, although significant, were small, which may be a result of a large sample size. Further replication is needed to determine the clinical importance of some of these findings.

For women with excessive worry, appropriate referrals could be targeted at their unique concerns. These interventions must be culturally sensitive, and tailored to differences in communication style, social support, and coping strategies. Continuing research must recognize the multifaceted nature of women's fears, including racial/ethnic variation and acculturation differences in worry. The influence of factors regarding a women's experience in the healthcare system deserves attention, as they hold promise for system and policy interventions.

# CONFLICT OF INTEREST DISCLOSURES

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# REFERENCES

- Lee-Jones C, Humphris G, Dixon R, Bebbington Hatcher M. Fear of cancer recurrence—a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psychooncology*. 1997;6:95-105.
- van den Beuken-van Everdingen MH, Peters ML, de Rijke JM, Schouten HC, van Kleef M, Patijn J. Concerns of former breast cancer patients about disease recurrence: a validation and prevalence study. *Psychooncology*. 2008;17:1137-1145.
- 3. Vickberg SM. The concerns about recurrence scale (CARS): a systematic measure of women's fears about the possibility of breast cancer recurrence. *Ann Behav Med.* 2003;25:16-24.
- Baker F, Denniston M, Smith T, West MM. Adult cancer survivors: how are they faring? *Cancer*. 2005;104:2565-2576.
- Kornblith AB, Powell M, Regan MM, et al. Long-term psychosocial adjustment of older vs younger survivors of breast and endometrial cancer. *Psychooncology*. 2007;16:895-903.
- Gill KM, Mishel MH, Belyea M, et al. Triggers of uncertainty about recurrence and long-term treatment side effects in older African American and Caucasian breast cancer survivors. Oncol Nurs Forum. 2004;31:633-639.
- Deimling GT, Bowman KF, Sterns S, Wagner LJ, Kahana B. Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psychooncol*ogy. 2006;16:306-320.
- 8. Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academy Press; 2006.
- 9. Hawley ST, Griggs JJ, Hamilton AS, et al. Decision involvement and receipt of mastectomy among racially and ethnically diverse breast cancer patients. *J Natl Cancer Inst.* 2009;101:1337-1347.
- Katz SJ, Lantz PM, Janz NK, et al. Patient involvement in surgery treatment decisions for breast cancer. *J Clin Oncol*. 2005;23:5526-5533.
- 11. McGuire KP, Santillan AA, Kaur P, et al. Are mastectomies on the rise? A 13-year trend analysis of the selection of mastectomy versus breast conservation therapy in 5865 patients. *Ann Surg Oncol.* 2009;16:2682-2690.
- 12. Gray RE, Fitch M, Greenberg M, Hampson A, Doherty M, Labrecque M. The needs of well, longer-term survivors of breast cancer. *Patient Educ Couns*. 1998;33:245-255.
- 13. Jiwa M, Thompson J, Coleman R, Reed M. Breast cancer follow-up: could primary care be the right venue? *Curr Med Res Opin.* 2006;22:625-630.
- 14. Costanzo ES, Lutgendorf SK, Mattes ML, et al. Adjusting to life after treatment: distress and quality of life following treatment for breast cancer. *Br J Cancer*. 2007;97:1625-1631.
- Sammarco A, Konecny LM. Quality of life, social support, and uncertainty among Latina breast cancer survivors. *Oncol Nurs Forum*. 2008;35:844-849.

- Clayton MF, Mishel MH, Belyea M. Testing a model of symptoms, communication, uncertainty, and well-being, in older breast cancer survivors. *Res Nurs Health*. 2006;29: 18-39
- 17. Spencer SM, Lehman JM, Wynings C, et al. Concerns about breast cancer and relations to psychosocial well-being in a multiethnic sample of early-stage patients. *Health Psychol.* 1999;18:159-168.
- Giedzinska AS, Meyerowitz BE, Ganz PA, Rowland JH. Health-related quality of life in a multiethnic sample of breast cancer survivors. *Ann Behav Med.* 2004;28:39-51.
- Patcher LM, Weller SC, Baer RD, et al. Variation in asthma beliefs and practices among mainland Puerto Ricans, Mexican-Americans, Mexicans, and Guatemalans. *J Asthma*. 2002;39:119-134.
- 20. Vega WA, Rodriguez MA, Gruskin E. Health disparities in the Latino population. *Epidemiol Rev.* 2009;31:99-112.
- 21. Ashing-Giwa KT, Padilla GV, Bohrquez DE, Tejero JS, Garcia M. Understanding the breast cancer experience of Latina women. *J Psychosoc Oncol.* 2006;24:19-52.
- Mellon S, Kershaw TS, Northouse LL, Freeman-Gibb L. A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psychooncology*. 2007;16: 214-223.
- 23. Janz NK, Mujahid MS, Lantz PM, et al. Population-based study of the relationship of treatment and scoiodemographics on quality of life for early stage breast cancer. *Qual Life Res.* 2005;14:1467-1479.
- 24. US Department of Health and Human Services. Epidemiologic Research in Hispanic Populations, Opportunities, Barriers and Solutions. December 3, 2003. Available at: http://www.nhlbi.nih.gov/meetings/workshops/hispanic.htm Accessed September 7, 2010.
- Greene FL, Page DL, Fleming ID, Fritz A, Balch CM.
   AJCC Cancer Staging Manual. 6th ed. Philadelphia, PA: Lippincott Raven Publishers; 2002.
- 26. Centers for Disease Control and Prevention National Cancer Institute. State Cancer Profiles: Dynamic Views for Cancer Statistics for Prioritizing Cancer Control Efforts in the Nation, States, and Counties. Available at: http://statecancerprofiles. cancer.gov/incidencerates/index.php Accessed October 22, 2010.
- Dillman DA. Mail and Telephone Surveys: The Total Design Method. New York, NY: Wiley; 1997.
- Lazarus RS. Evolution of a model of stress, coping, and discrete emotions. In Rice VH, ed. Handbook of Stress, Coping, and Health. Thousand Oaks, CA: Sage; 2000:195-222.
- Northouse LL, Mood D, Kershaw T, et al. Quality of life of women with recurrent breast cancer and their family members. J Clin Oncol. 2002;20:4050-4064.
- Marin G, Sabogal F, VanOss Marin B, Otero-Sabogal F, Perez-Stable EJ. Development of a short acculturation scale for Hispanics. *Hisp J Behav Sci.* 1987;9:183-205.

- Hamilton AS, Hofer TP, Hawley ST, et al. Latinas and breast cancer outcomes: population-based sampling, ethnic identity, and acculturation assessment. *Cancer Epidemiol Bio*markers Prev. 2009;18:2022-2029.
- 32. Hawley ST, Janz NK, Lillie SE, et al. Perceptions of care coordination in a population-based sample of diverse breast cancer patients. *Patient Educ Couns.* In press.
- McDonald KM, Dundaram V, Bravata DM, et al, eds. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies. Rockville, MD: Agency for Healthcare Research and Quality; 2007.
- Bickell NA, Young GJ. Coordination of care for early-stage breast cancer patients. J Gen Intern Med. 2001;16:737-742.
- Janz NK, Mujahid MS, Hawley ST, et al. Racial/ethnic differences in quality of life after diagnosis of breast cancer. *J Cancer Surviv.* 2009;4:212-222.
- Friedman LC, Kalidas M, Elledge R, et al. Optimism, social support and psychosocial functioning among women with breast cancer. *Psychooncology*. 2006;15:595-603.
- Ashing-Giwa K, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res.* 2007;16:413-428.
- 38. Burton AW, Fanciullo GJ, Beasley RD, Fisch MJ. Chronic pain in the cancer survivor: a new frontier. *Pain Med.* 2007;8:189-198.
- Zachariae R, Paulsen K, Mehlsen M, Jensen AB, Johansson A, von der Maase H. Chemotherapy-induced nausea, vomiting, and fatigue—the role of individual differences related to sensory perception and autonomic reactivity. *Psychother Psychosom.* 2007;76:376-384.
- Schnur JB, Ouellette SC, Dilorenzo TA, Green S, Montgomery, GH. A qualitative analysis of acute skin toxicity among breast cancer radiotherapy patients. *Psychooncology*. [published online ahead of print March 17, 2010.]
- Mathews A, Ridgeway V, Warren R, Britton P. Predicting worry following a diagnosis of breast cancer. *Psychooncology*. 2002;11:415-418.
- Janz NK, Mujahid MS, Hawley ST, Griggs JJ, Hamilton AS, Katz SJ. Racial/ethnic differences in adequacy of information and support for women with breast cancer. *Cancer*. 2008;113:1058-1067.
- 43. Armes J, Crowe M, Colbourne L, et al. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *J Clin Oncol.* 2009;27:6172-6179.
- 44. Ganz PA. Survivorship: adult cancer survivors. *Primary Care*. 2009;36:721-741.
- 45. Northouse LL. Mastectomy patients and the fear of cancer recurrence. *Cancer Nurs.* 1981;4:213-220.
- Cella D, Tulsky D, Gray G. The Functional Assessment of Cancer Therapy Scale: development and validation of the general measure. *J Clin Oncol.* 1993;11:570-579.