

Published in final edited form as:

*Cancer*. 2011 May 1; 117(9): 1827–1836. doi:10.1002/cncr.25740.

## Correlates of Worry about Recurrence in a Multi-Ethnic Population-Based Sample of Women with Breast Cancer

Nancy K. Janz, PhD<sup>1</sup>, Sarah T. Hawley, PhD, MPH<sup>2,3</sup>, Mahasin S. Mujahid, PhD<sup>4</sup>, Jennifer J. Griggs, MD, MPH<sup>3</sup>, Amy Alderman, MD, MPH<sup>5</sup>, Ann S. Hamilton, PhD<sup>6</sup>, John J. Graff, PhD<sup>7</sup>, Reshma Jagsi, MD, D. Phil<sup>8</sup>, and Steven J. Katz, MD, MPH<sup>2,3,9</sup>

<sup>1</sup>Department of Health Behavior and Health Education, University of Michigan School of Public Health, Ann Arbor MI

<sup>2</sup>Veterans Administration Center for Practice Management and Outcomes Research, Ann Arbor VA Health Care System, Ann Arbor MI

<sup>3</sup>Division of General Medicine, Department of Internal Medicine, University of Michigan Medical Center, Ann Arbor, MI

<sup>4</sup>Division of Epidemiology, University of California Berkeley, School of Public Health, Berkeley, CA

<sup>5</sup>Department of Surgery, University of Michigan, Ann Arbor, Michigan

<sup>6</sup>Department of Preventive Medicine, Keck School of Medicine, University of Southern California, Los Angeles, CA

<sup>7</sup>Cancer Institute of New Jersey, Robert Wood Johnson Medical School, New Brunswick, NJ

<sup>8</sup>Department of Radiation Oncology, University of Michigan, Ann Arbor, MI

<sup>9</sup>Department of Health Management and Policy, University of Michigan School of Public Health, Ann Arbor, MI

### Abstract

**Background**—Worry about recurrence (worry) is a persistent concern of breast cancer survivors. Little is known about whether race/ethnicity or health care experiences are associated with worry.

**Methods**—Women with non-metastatic breast cancer diagnosed from 6/05–2/07 and reported to Detroit or Los Angeles SEER registries were surveyed (mean 9 months post-diagnosis); 2290 responded (73%). Latina and African Americans (AA) 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 same breast, other breast, spreading to other parts of the body. Race/ethnicity categories were white, AA, and Latina (categorized into low vs. high acculturation). The worry scale was regressed on sociodemographics, clinical/treatment, and health care experience factors (e.g., care coordination collapsed into low, medium, high).

**Results**—Low acculturated Latinas reported more worry and AAs less worry than whites ( $p < 0.001$ ). Other factors independently associated with more worry were younger age, being employed, more pain and fatigue, and radiation ( $ps < 0.05$ ). With all factors in the model, less worry was associated (all  $ps < 0.05$ ) 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, and

high) and more coordinated care (3.36, 2.94, 2.82, for low, medium, high). Race/ethnicity remained significant controlling for all factors ( $p < 0.001$ ).

**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.

### Keywords

Breast cancer; recurrence; quality of life; minority health; health status disparities; quality of health care

## Introduction

Due to 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).<sup>8</sup> 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<sup>9-11</sup> and get bilateral versus single mastectomy.<sup>9</sup> Increased worry can deter women from seeking appropriate follow up care or may encourage maladaptive behaviors such as excessive checking.<sup>1,12</sup> Several studies have shown that high levels of worry can lead to depression, anxiety,<sup>1,7,13</sup> and decreased QOL.<sup>2,7,14-16</sup>

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. While Latinos are a racially and socioculturally heterogeneous population,<sup>19</sup> 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,<sup>15,17</sup> 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,<sup>10</sup> lower decision satisfaction,<sup>9</sup> 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,<sup>7,22</sup> while others have found receiving chemotherapy may be associated with worry.<sup>3,14,23</sup> Finally, few studies have examined factors in the health care experience (e.g., care coordination) that might elucidate differences in worry across vulnerable subgroups. Negotiating the health care system remains an understudied element of acculturation.<sup>24</sup> 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.<sup>24</sup>

To address these gaps in the literature, we used a large multi-ethnic 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 patient's appraisal of their health care 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 health care experience?

## Methods

### Study Population

Between June 2005 and February 2007, 3252 women aged 20-79 years diagnosed with primary ductal carcinoma in-situ (DCIS) 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) physician did not want 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, 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 to respondents, non-respondents were more likely to be African American (AA) (34.9% vs. 26.2%,  $p<.001$ ), unmarried (23.0% vs. 19.3%,  $p=.01$ ), 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 (LACSP) and the Metropolitan Detroit Cancer Surveillance System (MDCSS). All AA 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 U.S 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.<sup>26</sup> The Dillman survey method was employed to encourage survey response.<sup>27</sup> The study protocol was approved by the Institutional Review Boards of the University of Michigan, University of Southern California and Wayne State University.

### 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 (Figure 1). According to the framework, there are antecedent variables (e.g. person, illness related) and mediating variables (e.g. appraisal factors) that directly or indirectly affect QOL. We identified antecedent variables (categorized into person and clinical/treatment factors) and mediating factors (appraisal of health care experience) potentially affecting worry.

**Dependent Variable—**Worry about recurrence was assessed with three 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's alpha=0.88). 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 were combined to create the race/ethnicity variable. Women indicated their race (White, Black/AA, American Indian or Alaska Native, Asian or Pacific Islander, or other) and if they were Hispanic/Latina (yes/no). The Short Acculturation Scale for Hispanics (SASH), 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 four items in SASH 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 four categories (White, AA, Latinas-high acculturation [Latinas-high], and Latinas-low acculturation [Latinas-low]). Compared to 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), 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 health care experience was measured across three 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 1-5 with a mean of 4.32, and Cronbach's 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 1-5 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 five items, (5-point Likert scale, “never” to “always”): (1) how often patients received help from their surgeons with referrals to other physicians, (2) how often they knew who 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 doctors had the medical information they needed. The care coordination scale ranged from 1-5 with a mean of 4.50 and Cronbach's alpha of .697. Higher scores for all three health care experience measures indicate more understanding of information, better symptom management, and better coordination of care. Multi-item scales scores were calculated by averaging items. Each health care experience measure was collapsed into 3 ordinal categories (low, medium, high) to optimize the clarity of presentation. Other specifications of these variables (e.g. 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 non-response. 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 health care system factors. We also tested bivariate associations between sociodemographics and factors within the health care experience, an important step is assessing mediation. Multivariable 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 health care experience in Model 2 (research question 2). All two-way interactions between sociodemographics and health care experience factors were examined testing a moderating role (research question 3). All analyses were performed using SAS V9 programming.

### Results

Table 1 displays the sample characteristics overall and by mean worry scores. The mean age was 56.8 (SD=11.4) and 68.7 %, 14.3%, 8.1%, and 8.9% were white, AA, Latinas-high, and Latinas-low respectively. In bivariate analyses, there were significant differences in mean worry scores (all p values <0.001) for all sociodemographic variables except level of income.

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 <0.05). Women who had lumpectomy compared to mastectomy reported more worry, as did women who received radiation and/or chemotherapy (all ps <0.05).

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 percent of women reporting levels of worry by race/ethnicity. Almost 29% of AA women expressed low levels of worry (corresponding to “not at all”) compared to 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 to 25%, 13%, and 14% for Latinas-high, AA, and white women, respectively.

Figure 3 displays unadjusted mean worry scores for the three health care experience factors. Greater ease in understanding information (3.14, 3.01, 2.68 for low, medium and high,  $p < 0.001$ ), better symptom management (3.31, 2.85, 2.76 for low, medium, and high,  $p = 0.001$ ) and more coordinated care (3.39, 2.91, 2.73, for low, medium, and high,  $p < 0.001$ ) were all significantly associated with lower levels of worry.

In the multivariable 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  $p$ s  $< 0.05$ ). More worry was reported by Latinas (low and high) than whites, and women who were younger, employed, had more comorbidities, had more pain and fatigue, and who received radiation. In Model 2 that further adjusted for the three factors from the health care experience, associations were only slightly reduced for sociodemographics, clinical and treatment factors, with the exception of the number of comorbidities where the associations were reduced and no longer significant ( $p = 0.091$ ). In this model, Latinas-low reported more worry than other groups, worry scores 3.80 vs. 3.17, 2.59, 2.90 for Latinas-high, AAs, and whites ( $p < 0.001$ ). While 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 ( $p = 0.044$ ), and more coordinated care ( $p = 0.012$ ). We did not find any significant interactions between sociodemographics and health care experience factors, suggesting that sociodemographic factors and worry scores were not modified by health care 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 health care 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 more emotional distress,<sup>15,17</sup> but to our knowledge no previous study has examined worry by level of acculturation. In contrast, AA women reported lower levels of worry, lending support to the growing literature that AA 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 with fewer coping resources.<sup>14</sup> While education did not remain significant in the full model, being employed was associated with more worry. Women who are employed may worry more due to 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 (i.e. somatoform amplification),<sup>39</sup> and/or women who were anxious reported more symptoms.<sup>40</sup> In addition, the presence of comorbidities may make it more difficult to interpret whether symptoms are due to cancer, resulting in higher worry. Cancer stage was not independently associated with more worry, consistent with many other studies.<sup>3,14,22,41</sup> 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.<sup>3,14,22</sup> Women who received radiation reported more worry while 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, as well as others<sup>21</sup> support that difficulty understanding information and establishing a good relationship with their physician could contribute to greater worry. While 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.<sup>43</sup> The IOM report on cancer survivors recommends patients receive a comprehensive care summary and follow-up plan to inform and coordinate delivery of care,<sup>8,44</sup> 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 health care system experiences were assessed. Culture could impact communication styles and/or perceptions of worry. For AA women it may be culturally appropriate to present a strong image, thereby reporting less worry, while for Latinas it may be culturally appropriate to express concerns and greater distress.<sup>17</sup> 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<sup>18</sup> and utilize more religious-oriented coping<sup>17</sup> than whites, while low acculturated Latinas report the lowest level of social support.<sup>37,42</sup>

Study findings are limited by the cross-sectional design that did not allow for examination of worry over time. Multi-ethnic 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.<sup>3,45</sup> While 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)<sup>46</sup> subscales as follows: physical well-being scale:  $\text{corr} = -.313$  ( $p < .001$ ) and emotional well-being scale:  $\text{corr} = -.577$  ( $p < .001$ ) (unpublished).

Our study measures were self reported and may be subject to recall bias due to 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 vs. other groups across a broad array of outcomes.<sup>9,10,35</sup> 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 U.S. 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 health care 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 health care system deserves attention as they hold promise for system and policy interventions.

## Acknowledgments

This work was funded by grant R01 CA8837-A1 from the National Cancer Institute to the University of Michigan. The collection of cancer incidence data used in this study was supported by the California Department of Health Services as part of the statewide cancer reporting program mandated by California Health and Safety Code Section 103885; the National Cancer Institute's Surveillance, Epidemiology and End Results Program under contract N01-PC-67010 awarded to the University of Southern California, and contract N02-PC-15105 awarded to the Public Health Institute; and the Centers for Disease Control and Prevention's National Program of Cancer Registries, under agreement #U55/CCR921930 awarded to the Public Health Institute. The collection of metropolitan Detroit cancer incidence data was supported by the NCI SEER Program contract N01-PC-65064. The ideas and opinions expressed herein are those of the author(s), and endorsement by the State of California, Department of Public Health the National Cancer Institute, and the Centers for Disease Control and Prevention or their Contractors and Subcontractors is not intended nor should be inferred. Dr. Jaggi was supported by the American Cancer Society.

This work was supported by the N.C.I. (5R01CA109696-03 to the University of Michigan)

## Reference List

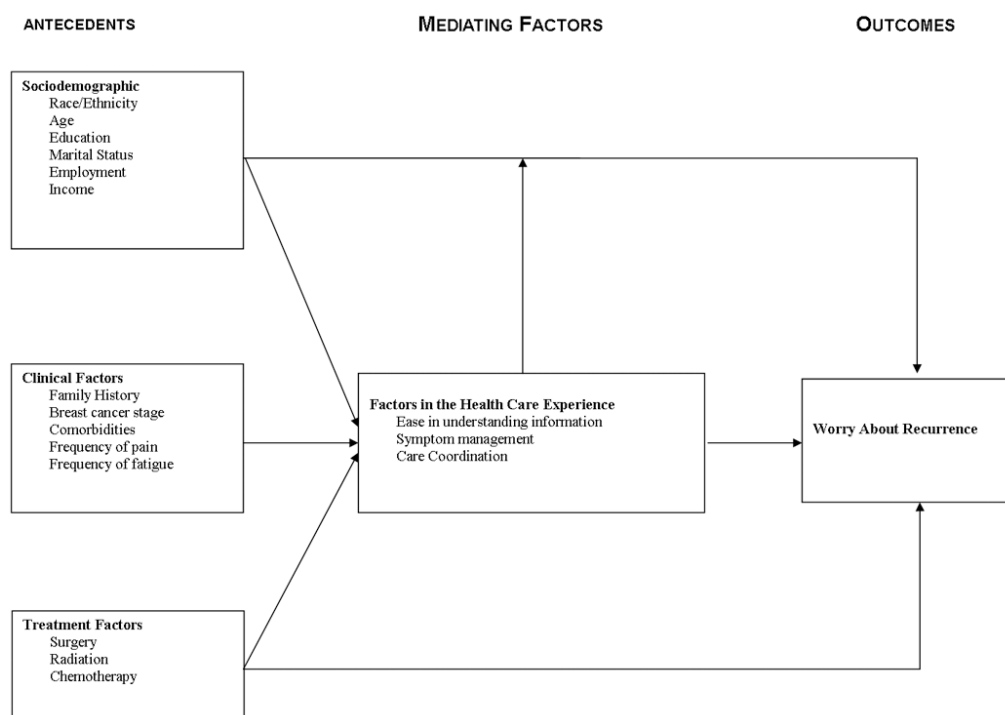
1. Lee-Jones C, Humphris G, Dixon R, Bebbington Hatcher M. Fear of cancer recurrence -- A literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-Oncology*. 1997; 6:95–105. [PubMed: 9205967]
2. van den Beuken-van Everdingen MH, Peters ML, de Rijke JM, Schouten HC, van Kleef M, Patijn J. Concerns of former breast cancer patients about disease recurrence: A validation and prevalence study. *Psycho-Oncology*. 2008; 17:1137–1145. [PubMed: 18484568]
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. [PubMed: 12581932]
4. Baker F, Denniston M, Smith T, West MM. Adult cancer survivors: How are they faring? *Cancer*. 2005; 104:2565–2576. [PubMed: 16258929]
5. Kornblith AB, Powell M, Regan MM, Bennett S, Krasner C, Moy B, et al. Long-term psychosocial adjustment of older vs younger survivors of breast and endometrial cancer. *Psycho-Oncology*. 2007; 16:895–903. [PubMed: 17245695]



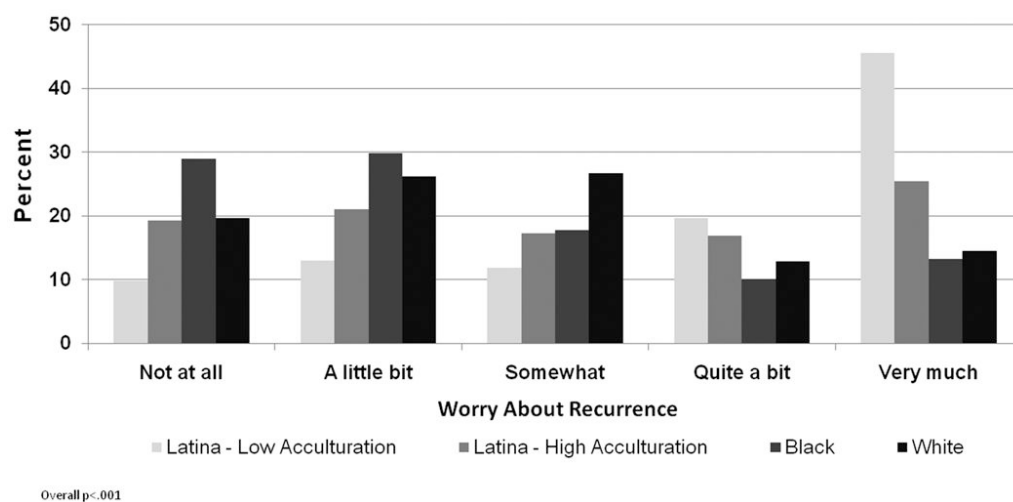
6. Gill KM, Mishel MH, Belyea M, Germino B, Porter LS, Carlton LaNey I, et al. Triggers of uncertainty about recurrence and long-term treatment side effects in older African American and Caucasian breast cancer survivors. *Oncol Nurs Forum*. 2004; 31:633–639. [PubMed: 15146229]
7. Deimling GT, Bowman KF, Sterns S, Wagner LJ, Kahana B. Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology*. 2006; 16:306–320. [PubMed: 16041841]
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, Graff JJ, Janz NK, Morrow M, Jagsi R, Salem B, Katz SJ. Decision involvement and receipt of mastectomy among racially and ethnically diverse breast cancer patients. *J Natl Cancer Inst*. 2009; 101:1337–1347. [PubMed: 19720966]
10. Katz SJ, Lantz PM, Janz NK, Fagerlin A, Schwartz K, Liu L, et al. Patient involvement in surgery treatment decisions for breast cancer. *J Clin Oncol*. 2005; 23:5526–5533. [PubMed: 16110013]
11. McGuire KP, Santillan AA, Kaur P, Meade T, Parbhoo J, Mathias M, 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. [PubMed: 19653046]
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. [PubMed: 9731162]
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. [PubMed: 16684422]
14. Costanzo ES, Lutendorf SK, Mattes ML, Trehan S, Robinson CB, Tewfik F, et al. Adjusting to life after treatment: Distress and quality of life following treatment for breast cancer. *Br J Cancer*. 2007; 97:1625–1631. [PubMed: 18000503]
15. Sammarco A, Konecny LM. Quality of life, social support, and uncertainty among Latina breast cancer survivors. *Oncol Nurs Forum*. 2008; 35:844–849. [PubMed: 18765332]
16. 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. [PubMed: 16404732]
17. Spencer SM, Lehman JM, Wynings C, Arena P, Carver CS, Antoni MH, et al. Concerns about breast cancer and relations to psychosocial well-being in a multiethnic sample of early-stage patients. *Health Psychology*. 1999; 18:159–168. [PubMed: 10194051]
18. 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. [PubMed: 15249258]
19. Patcher LM, Weller SC, Baer RD, de Alba Garcia JE, Trotter RT, Glazer M, et al. Variation in asthma beliefs and practices among mainland Puerto Ricans, Mexican-Americans, Mexicans, and Guatemalans. *J Asthma*. 2002; 39(2):119–134. [PubMed: 11995676]
20. Vega WA, Rodriguez MA, Gruskin E. Health disparities in the Latino population. *Epidemiologic Reviews*. 2009; 31:99–112. [PubMed: 19713270]
21. Ashing-Giwa KT, Padilla GV, Bohrquez DE, Tejero JS, Garcia M. Understanding the breast cancer experience of Latina women. *Journal of Psychosocial Oncology*. 2006; 24(3):19–52. [PubMed: 17088240]
22. Mellon, S.; Kershaw, TS.; Northouse, LL.; Freeman-Gibb, LA. *Psycho-Oncology*. Vol. 16. 2007. LA family-based model to predict fear of recurrence for cancer survivors and their caregivers; p. 214–223.
23. Janz NK, Mujahid MS, Lantz PM, Fagerlin A, Salem B, Morrow M, Deapen D, Katz SJ. Population-based study of the relationship of treatment and sociodemographics on quality of life for early stage breast cancer. *Qual Life Res*. 2005; 14:1467–1479. [PubMed: 16110927]
24. U.S. Department of Health and Human Services. [Retrieved September 7, 2010] *Epidemiologic Research in Hispanic Populations, Opportunities, Barriers and Solutions*. 2003 December 3. <http://www.nhlbi.nih.gov/meetings/workshops/hispanic.htm>
25. Greene, FL.; Page, DL.; Fleming, ID.; Fritz, A.; Balch, CM. *AJCC cancer staging manual*. 6th. Philadelphia: Lippincott Raven Publishers; 2002.

26. CDC National Cancer Institute. State cancer profiles: dynamic views for cancer statistics for prioritizing cancer control efforts in the nation, states, and counties. (n.d.). Retrieved from <http://statecancerprofiles.cancer.gov/incidencerates/index.php>
27. Dillman, DA. Mail and telephone surveys: the total design method. New York: Wiley; 1997.
28. Lazarus, RS. Evolution of a model of stress, coping, and discrete emotions. In: Rice, VH., editor. Handbook of stress, coping, and health. Thousand Oaks, CA: Sage; 2000. p. 195-222.
29. Northouse LL, Mood D, Kershaw T, Schafenacker A, Mellon S, Walker J, et al. Quality of life of women with recurrent breast cancer and their family members. *J Clin Oncol*. 2002; 20:4050–4064. [PubMed: 12351603]
30. Marín G, Sabogal F, VanOss Marín B, Otero-Sabogal F, Pérez-Stable EJ. Development of a short acculturation scale for Hispanics. *Hispanic Journal of Behavioral Sciences*. 1987; 9:183–205.
31. Hamilton AS, Hofer TP, Hawley ST, Morrell D, Leventhal M, Deapen D, Salem B, Katz SJ. Latinas and breast cancer outcomes: Population-based sampling, ethnic identity, and acculturation assessment. *Cancer Epidemiol Biomarkers Prev*. 2009; 18:2022–2029. [PubMed: 19549806]
32. Hawley ST, Janz NK, Lillie SE, Friese CR, Griggs JJ, Graff JJ, Hamilton AS, Jain S, Katz SJ. Perceptions of care coordination in a population-based sample of diverse breast cancer patients. 2010 in press.
33. McDonald, KM.; Dundaram, V.; Bravata, DM.; Lewis, R.; Lin, N.; Kraft, S., et al., editors. Technical Review 9 (prepared by the Stanford University UCSF Evidence Based Practice Center under contract 290-02-0017) AHRQ publication no 04(07)-0051-7. Rockville, MD: Agency for Healthcare Research and Quality; June. 2007 Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies.
34. Bickell NA, Young GJ. Coordination of care for early-stage breast cancer patients. *J Gen Intern Med*. 2001; 16(11):737–742. [PubMed: 11722686]
35. Janz NK, Mujahid MS, Hawley ST, Griggs JJ, Alderman A, Hamilton AS, et al. Racial/ethnic differences in quality of life after diagnosis of breast cancer. *J Cancer Surviv*. 2009; 4:212–222. [PubMed: 19760151]
36. Friedman LC, Kalidas M, Elledge R, Chang J, Romero C, Husain I, Dulay MF, Liscum KR. Optimism, social support and psychosocial functioning among women with breast cancer. *Psycho-Oncology*. 2006; 15:595–603. [PubMed: 16287209]
37. 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. [PubMed: 17279444]
38. Burton AW, Fanciullo GJ, Beasley RD, Fisch MJ. Chronic pain in the cancer survivor: A new frontier. *Pain Medicine*. 2007; 8(2):189–198. [PubMed: 17305690]
39. 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. *Psychotherapy and Psychosomatics*. 2007; 76(6):376–384. [PubMed: 17917474]
40. Schnur JB, Ouellette SC, Dileo TA, Green S, Montgomery GH. A qualitative analysis of acute skin toxicity among breast cancer radiotherapy patients. *Psycho-Oncology*. 2010 Epub ahead of print.
41. Mathews A, Ridgeway V, Warren R, Britton P. Predicting worry following a diagnosis of breast cancer. *Psycho-Oncology*. 2002; 11:415–418. [PubMed: 12228874]
42. 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. [PubMed: 18618494]
43. Arnes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, et al. Patients' supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. *J Clin Oncol*. 2009; 27:6172–6179. [PubMed: 19884548]
44. Ganz PA. Survivorship: Adult cancer survivors. *Primary Care*. 2009; 36:721–741. [PubMed: 19913184]
45. Northouse LL. Mastectomy patients and the fear of cancer recurrence. *Cancer Nurs*. 1981; 4:213–220. [PubMed: 6909039]

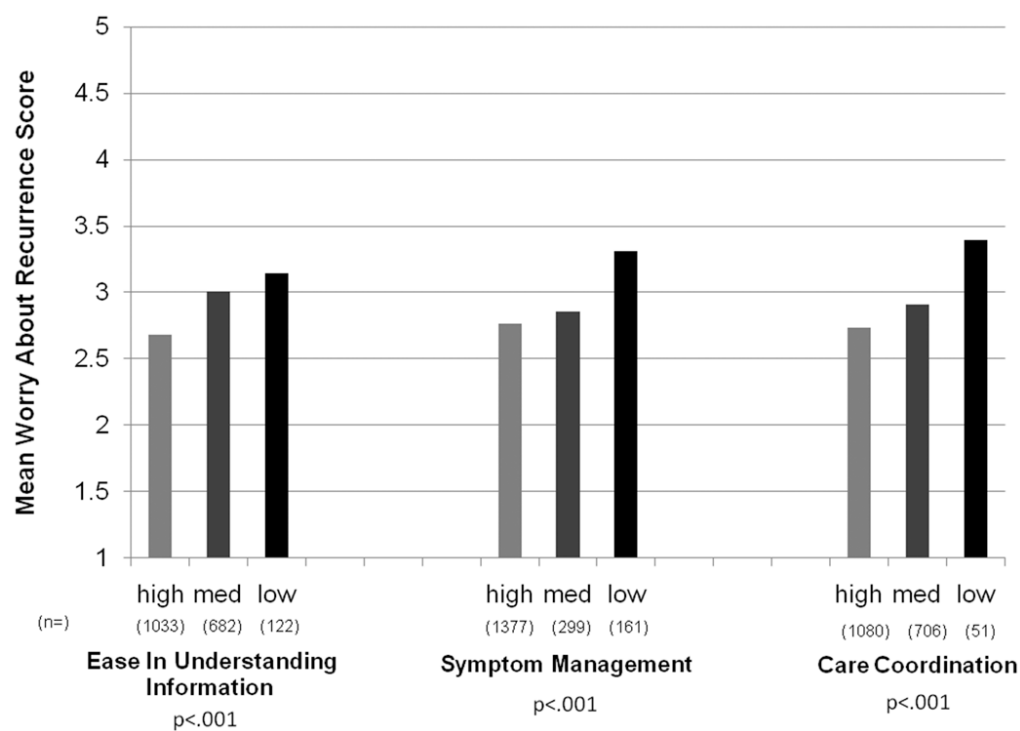
46. Cella D, Tulsky D, Gray G. The Functional Assessment of Cancer Therapy Scale: Development and Validation of the General Measure. *J Clin Oncol.* 1993; 11:570–579. [PubMed: 8445433]



**Figure 1. Modified stress/appraisal theoretical framework**



**Figure 2. Percent of women reporting levels of worry by race/ethnicity**



**Figure 3. Unadjusted mean worry scores for three health care experience factors**



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

	Overall		Mean Worry About Recurrence Score (range 1-5)	p-value
	N	%*		
<b><u>Sociodemographic</u></b>				
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				<.001
<50	526	25.8	3.17	
50-70	1064	59.6	2.81	
>70	247	114.6	2.27	
Education				<.001
< H.S. diploma	331	12.7	3.23	
H.S. diploma	374	19.3	2.86	
> H.S. diploma	1132	68.0	2.73	
Employed				<.001
Yes	1061	58.6	2.92	
No	776	41.4	2.68	
Marital status				0.004
Married/partner	1049	60.6	2.89	
Unmarried	788	39.4	2.72	
Income				0.274
<\$20,000	327	13.5	2.92	
\$20,000- \$69,999	677	36.4	2.84	
\$70,000 or more	505	32.4	2.75	
Missing	328	17.7	2.83	
<b><u>Clinical Factors</u></b>				
Family history				0.282
1 <sup>st</sup> degree relative	342	19.4	2.76	
No first degree relative	1495	80.6	2.84	
Breast cancer stage				0.007
0	352	19.5	2.66	
I	690	40.0	2.81	
II/III	795	40.5	2.91	
Number of co-morbidities				0.024
None	749	42.2	2.91	
One	540	30.7	2.74	
Two or more	548	27.1	2.77	
Frequency of Pain				<.001

	Overall		Mean Worry About Recurrence Score (range 1-5)	p-value
	N	%*		
None/A little	1029	56.5	2.55	
Some	592	32.0	3.11	
Quite a bit/ Very Much	216	11.5	3.32	
Frequency of Fatigue				<.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	
<b><u>Treatment Factors</u></b>				
Surgical Procedure				0.048
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				<.001
Yes	954	47.6	2.97	
No	883	52.4	2.68	

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

	Model 1 <sup>a</sup>	p-value	Model 2 <sup>a</sup>	p-value
<b><u>Sociodemographic</u></b>				
Race/ethnicity		<.001		<.001
Latina (low acculturation)	.907*		.862*	
Latina (high acculturation)	.272*		.250*	
African American	-.311*		-.313*	
White	-		-	
Age		<.001		<.001
<50	-		-	
50-70	-.364*		-.340*	
>70	-.772*		-.745*	
Education		.115		.183
< H.S. diploma	-		-	
H.S. diploma	.084		.080	
> H.S. diploma	-.060		-.048	
Marital status		.073		.079
Married/partner	.106		.104	
Not Married	-		-	
Employed (yes)	.132*	.028	.120*	.045
Income		.096		.116
<\$20,000	-		-	
\$20,000- \$69,999	.044		.066	
\$70,000 or more	-.126		-.096	
Missing	.002		.019	
<b><u>Clinical Factors</u></b>				
Family history		.992		.941
1 <sup>st</sup> degree relative	-.001		.005	
Breast cancer stage		.449		.451
0	-		-	
I	.051		.084	
II/III	.115		.105	
Number of co-morbidities		.044		.091
None	-		-	
One	.007		.010	
Two or more	.161*		.143	
Frequency of Pain		<.001		<.001
None/a little	-		-	
Some	.333*		.321*	
Quite a bit/ Very Much	.487*		.477*	

	Model 1 <sup>a</sup>	p-value	Model 2 <sup>a</sup>	p-value
Frequency of Fatigue		<.001		<.001
None/a little	-		-	
Some	.126		.122	
Quite a bit/ Very Much	.398*		.388*	
<b><u>Treatment Factors</u></b>				
Surgical Procedure		.120		.100
Lumpectomy	-		-	
Mastectomy	-.108		-.113	
Radiation therapy (yes)	.285*	<.001	.290*	<.001
Chemotherapy (yes)	-.031	.657	-.113	
<b><u>Factors in the Health Care Experience</u></b>				
Ease in understanding information				.047
High			-	
Medium			.135*	
Low			.009	
Symptom management				.029
High			-	
Medium			-.033	
Low			.244*	
Care coordination				.015
High			-	
Medium			.106*	
Low			.173*	