


# Disparities in the Survivorship Experience Among Latina Survivors of Breast Cancer

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**BACKGROUND:** The authors investigated disparities in the survivorship experience among Latinas with breast cancer (BC) in comparison with non-Latinas. **METHODS:** A cross-sectional bilingual telephone survey was conducted among 212 Latina and non-Latina women within 10 to 24 months after a diagnosis of BC (AJCC TNM staging system stage 0-III) at 2 Los Angeles County public hospitals. Data were collected using the Preparing for Life as a (New) Survivor (PLANS) scale, Perceived Efficacy in Patient-Physician Interactions Questionnaire (PEPPI), Breast Cancer Prevention Trial (BCPT) Symptom Checklist, Satisfaction with Care and Information Scale, Consumer Assessment of Healthcare Providers and Systems (CAHPS) tool, Charlson Comorbidity Index adapted for patient self-report, and the 12-item Short Form Health Survey. Controlling variables included age, stage as determined by the American Joint Committee on Cancer (AJCC) TNM staging system, educational level, and study site in multivariate analyses. **RESULTS:** The mean ages of Latinas and non-Latinas were 51.5 years and 56.6 years, respectively. Compared with non-Latinas, Latinas reported less BC survivorship knowledge (27.3 vs 30.7;  $P < .0001$ ), were more dissatisfied with BC care information (2.3 vs 3.4;  $P < .0001$ ), reported lower PEPPI scores (38.2 vs 42.2;  $P = .03$ ), and experienced more BCPT symptoms (6.4 vs 5.0;  $P = .04$ ). No differences were noted regarding their confidence in survivorship care preparedness (42.7 vs 41;  $P = .191$ ), satisfaction with BC survivorship care (9.6 vs 8.8;  $P = .298$ ), or their discussion with physicians (9.6 vs 8.1;  $P = .07$ ). These ethnic group differences persisted in multivariate analyses, with the exception of PEPPI. **CONCLUSIONS:** Latina survivors of BC experienced disparities in BC knowledge and satisfaction with information received, but believed themselves to be prepared for survivorship and were as satisfied with providers, care received, and discussions with physicians as non-Latinas. *Cancer* 2018;124:2373-80. © 2018 American Cancer Society.

**KEYWORDS:** breast cancer, disparity, knowledge, Latina, preparedness, satisfaction, survivorship.

## INTRODUCTION

In the United States, breast carcinoma (BC) is the most common malignancy among women, with an estimated 252,710 new cases diagnosed in 2017.<sup>1</sup> The number of survivors of BC is expected to grow dramatically given the expected increase in incidence and continued improvements in the detection and successful treatment of the disease. Patients who have had BC experience impaired quality of life, bothersome symptoms, and clinical difficulties after treatment.<sup>2,3</sup> Many of these posttreatment issues may evade attention because of diminishing contact with cancer specialists after initial treatment is over, a lack of expertise among primary care providers in dealing with such side effects, a lack of a standard protocol for follow-up after treatment, and nonspecific guidelines for dealing with these issues.

Accordingly, women with BC report a high need for information regarding cancer-related issues after treatment, needs that to our knowledge are largely unmet.<sup>4,5</sup> These challenges often are exacerbated among racial and ethnic minority populations by structural barriers and inequalities that preclude access to quality health care as well as information,<sup>6,7</sup> but to our knowledge less is known regarding the challenges of survivorship and follow-up care faced by minorities. In this regard, Latinas (who, at 17% of the US population, represent the largest and fastest growing ethnic minority group) have been shown in previous studies to be among the most vulnerable.<sup>7-9</sup>

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Language and educational attainment account for some of the primary barriers to quality care and effective patient-physician communication, and these disproportionately affect Latinas.<sup>10-12</sup> Better patient-physician communication in the form of physician information giving and patient self-efficacy in interacting with physicians have been shown to be linked to improved medical outcomes among low-income and racial/ethnic minority populations with regard to BC treatment-related symptoms and health-related quality of life.<sup>12-14</sup> In a longitudinal study, patients with BC who reported receiving greater physician information and having greater self-efficacy in interacting with physicians at the initiation of treatment reported better quality of life over the subsequent 5 years.<sup>14</sup> Satisfaction with survivorship information also is a strong predictor of vitality and mental health.<sup>4</sup> In the same vein, evidence suggests that patient satisfaction is a strong correlate of survival as well as quality of survivorship, and language, literacy, and culture barriers faced by Latinas negatively affect survival as well as quality of survivorship.<sup>15,16</sup>

The current study analyzed data from the baseline questionnaire of a randomized controlled trial of survivorship care plans in low-income survivors of BC<sup>17</sup> to assess gaps in knowledge, survivorship preparedness, and satisfaction with information received between Latinas and non-Latina patients.

## MATERIALS AND METHODS

### **Recruitment**

We conducted a baseline, cross-sectional survey to assess survivorship knowledge, preparedness, and satisfaction among a low-income population of women with BC who were enrolled in a randomized controlled trial of survivorship care plans.<sup>17</sup> Participants were recruited from 2 breast clinics located in the Los Angeles area: Harbor-University of California at Los Angeles (UCLA) Medical Center and Los Angeles County + University of Southern California (LAC + USC) Medical Center. Both facilities are public county institutions that serve the underserved population of LAC. The study was approved by the institutional review boards of both county hospitals and UCLA.

Eligibility criteria used in the recruitment process were English-speaking or Spanish-speaking females aged  $\geq 21$  years with a diagnosis of ductal carcinoma in situ or AJCC TNM staging system stage I, II, or III breast cancer for the first time within 10 and 24 months and who were at least 1 month after chemotherapy. Exclusion criteria included those with a previous cancer (except nonmelanomatous skin cancers or in situ [nonbreast] cancers), pregnant and lactating women, patients currently receiving

trastuzumab or other parenteral anticancer therapy, those with metastatic disease, women with clinically apparent cognitive or psychiatric impairment, those participating in another research study, patients currently being treated for another cancer, unwillingness to sign the medical record release form, or not living in LAC at the time of the study. Contact information for potential participants was extracted from the electronic databases at the participating breast clinic sites and was shared with the study staff.

Recruitment for the study began in 2012. Letters describing the project and inviting women to participate were mailed to 824 women from the 2 county public hospital study sites. In total, 212 eligible participants enrolled in the study and completed the baseline interview. Figure 1 shows the flow of recruitment into the study through randomization and completion of the baseline interview.

### **Questionnaire Design and Use**

All eligible participants completed a questionnaire to collect information regarding sociodemographics, comorbidities, BC survivorship knowledge, preparedness for survivorship, survivorship needs and concerns, physical and mental health status, satisfaction with care and communication, and receipt of appropriate follow-up survivorship care. The questionnaire was administered over the telephone by a trained, bilingual interviewer. The process used to translate the measures not readily available in Spanish included: 1) independent forward translation of the instrument into Spanish and independent back translation into English; 2) an independent conceptual equivalence rating of the back-translation and the source by a professional translator, a research assistant, and a lay person; and 3) modification or retranslation of items with low conceptual equivalence ratings. Translation was geared toward the Mexican American subpopulation of Spanish-speaking residents of California because US Census data showed that approximately 75% of Hispanics in LAC are Mexican in origin.<sup>18</sup>

### **Measures**

#### **Outcome variables**

Outcome variables included knowledge about survivorship issues, BC survivorship preparedness, patient-perceived efficacy in patient-physician interactions, BC-related symptoms, satisfaction with BC information received, satisfaction with BC survivorship care, and satisfaction with survivorship care discussion with physicians. They were assessed as follows.

#### **Knowledge about survivorship issues**

This was measured using the first part of a 2-part Preparing for Life as a (New) Survivor (PLANS) scale consisting of 11 items.<sup>19</sup>

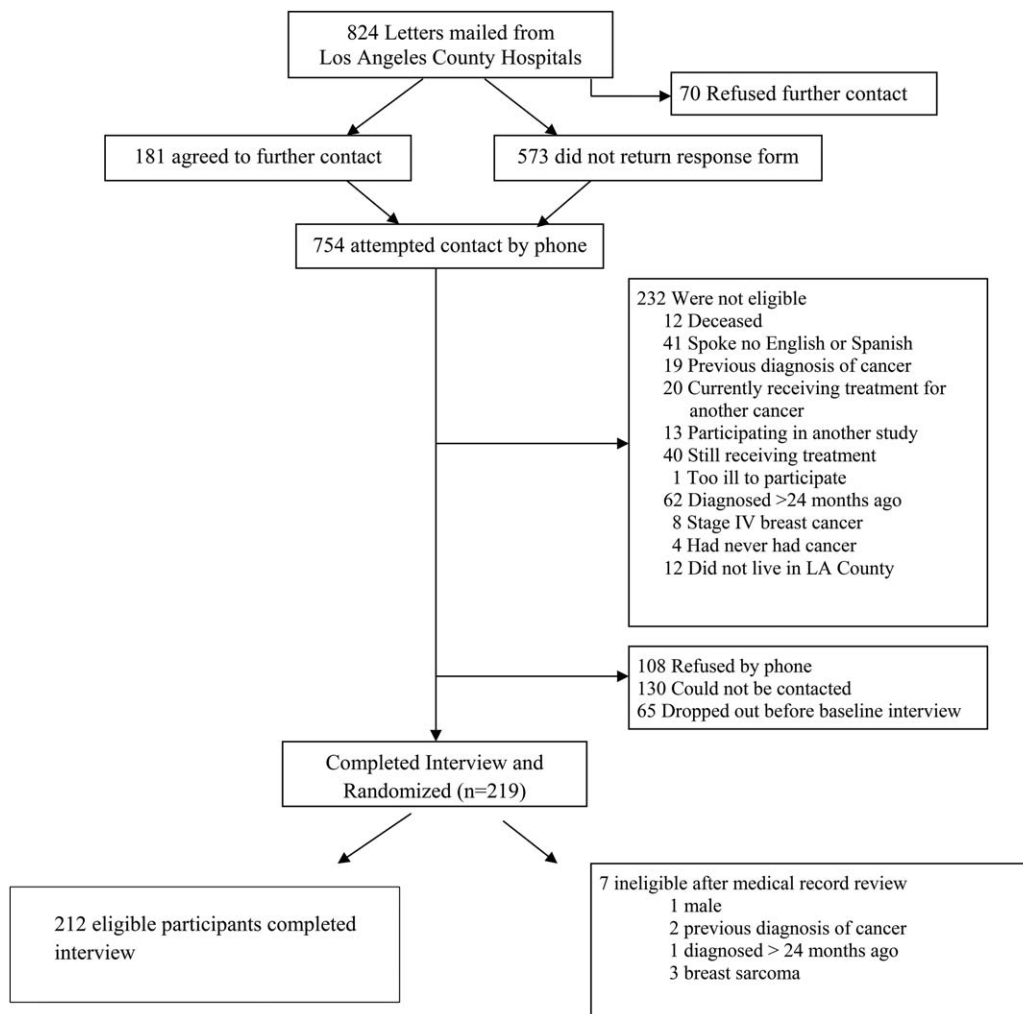


Figure 1. Study flow diagram. LA indicates Los Angeles.

**Preparedness about survivorship issues**

Patients’ preparedness with regard to BC follow-up care tasks was measured using the second part of the PLANS scale consisting of 5 items.

**Patient self-efficacy**

To measure a patient’s self-efficacy in obtaining medical information and receiving attention to their medical concerns from physicians, we used the Perceived Efficacy in Patient-Physician Interactions Questionnaire (PEPPI) using the 5-item version of the instrument, which has demonstrated a Cronbach alpha of .91.<sup>20</sup>

**Breast Cancer Prevention Trial symptoms**

An 18-symptom checklist adapted from the Breast Cancer Prevention Trial (BCPT) study that captures commonly reported physical and psychological symptoms as well as

symptoms possibly associated with menopause and tamoxifen use in survivors of BC was used in capturing symptoms.<sup>21</sup> Women who reported experiencing the symptom “moderately,” “quite a bit,” or “extremely” were considered to have the symptom in the analysis.

**Satisfaction With Care and Information Scale**

We used a 23-item survey instrument to measure patient satisfaction with survivorship care and information.<sup>4</sup>

**Satisfaction with survivorship care**

We used the Athena Post-Treatment Survey, Satisfaction with Medical Care, adapted from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey. The CAHPS is a research-based survey measurement tool that is widely used for assessing access, communication, and other aspects of the health care experience.<sup>22</sup>

This is a 1-item survey that asks survivors, “Overall, on a scale of 0 to 10, with 0 being the worst and 10 being the best, how would you rate your doctors or nurses that provided your breast cancer follow-up care?”

### Satisfaction with survivorship care discussion with physician

This is also a 1-item survey adapted from CAHPS. It asks survivors to rate how satisfied they were with the discussions with their physicians regarding their BC follow-up care on a scale of 0 to 10, with 0 indicating not at all satisfied and 10 indicating very satisfied.

### Independent variables

The key covariate of interest was ethnicity, which was self-reported. Control variables included patient sociodemographic characteristics such as age, highest level of education attained, marital/partner status, employment status, the Charlson Comorbidity Index adapted for patient self-report,<sup>23,24</sup> stage as determined by the American Joint Committee on Cancer (AJCC) TNM staging system, and the Mental Component Score and the Physical Component Score from the 12-item Short Form Health Survey (SF-12 MCS and SF-12 PCS, respectively).<sup>25</sup>

### Data Analyses

Descriptive measures, including means, counts, and percentages as appropriate, were assessed. Chi-square tests and Student *t* tests were used to compare demographic and clinical characteristics and key outcome measures between Latina and non-Latina survivors of BC. Mixed effects regression (PROC Mixed; SAS Institute Inc, Cary, North Carolina) models with hospital-level random effects first were used to assess ethnic differences on the outcome measures. We included the hospital-level random effect to account for potential correlations within hospitals. However, the results indicated that the G matrix was not positively definite; thus, the hospital-level random effect was removed. We then examined the ethnic differences adjusted for sociodemographic factors (age, educational level, and employment) and clinical characteristics (comorbidity, SF-12 MCS, and SF-12 PCS) using multiple linear regression, with hospital as a fixed effect. All statistical analyses were conducted using SAS statistical software (version 9.1; SAS Institute Inc); 2-sided alpha levels with *P* values <.05 were considered to be statistically significant.

## RESULTS

A total of 212 survivors of BC completed the baseline interview: 58 non-Latinas and 154 Latinas. The non-Latina group

**TABLE 1.** Descriptive Statistics of the Sample (N = 212)

Characteristic	Latinas N = 154	Non-Latinas N = 58	<i>P</i>
Mean age (SD) [range], y	51.5 (10.1) [29-78]	56.6 (7.6) [37-85]	.0001
Education, no. (%)			<.0001
≥High school	37 (24.0)	52 (89.7)	
Income, no. (%)			.026
<\$30,000	146 (94.8)	49 (84.5)	
\$30,000-\$49,999	7 (4.6)	6 (10.3)	
≥\$50,000	1 (0.7)	3 (5.2)	
Married/partnered, no. (%)			<.0001
Yes	89 (57.8)	15 (25.9)	
Employed, no. (%)			.322
Yes	45 (27.4)	13 (22.4)	
Comorbidity, no. (%)			.811
1	44 (28.6)	13 (22.4)	
≥2	32 (20.8)	14 (24.1)	
Mean time since BC diagnosis (SD) [range], mo	17.7 (5.1)	19.2 (5.5)	.198
General health status, no. (%)			.277
Poor/fair	63 (40.9)	19 (32.8)	
Usual source of care, no. (%)			.428
Yes	134 (87.0)	48 (82.8)	
Mean SF-12 measures (SD)			
MCS	42.6 (13.2)	45.5 (12.7)	.156
PCS	41.0 (9.2)	39.9 (9.1)	.462

Abbreviations: BC, breast carcinoma; MCS, Mental Component Score; PCS, Physical Component Score; SD, standard deviation; SF-12, 12-item Short Form Health Survey.

included 33 black, 10 white, and 6 Asian women; 7 women reported multiple ethnicities and 2 checked off “other.”

Table 1 shows the descriptive statistics of these women. Latina survivors were significantly younger than their non-Latina counterparts (51.5 years vs 56.6 years; *P* = .0001) and were more likely to be partnered (57.8% vs 25.9%; *P* <.0001), but were less likely to have enough money to cover their needs, with approximately 95% of Latinas reporting an annual household income of <\$30,000 (vs 84.5% for non-Latinas; *P* = .026). Other demographic disparities include educational attainment, with 89.7% of the non-Latinas having a high school degree or higher, whereas only 24.0% of Latinas had a high school degree or higher (*P* <.0001).

In general, both groups reported lower scores than the SF-12 national general population norms for the MCS (42.6 for Latinas and 45.5 for non-Latinas) and the PCS (41.0 for Latinas and 39.9 for non-Latinas); had a usual source of care other than BC clinical care (87.0% and 82.8%, respectively); and experienced similar rates of employment (27.4% of Latinas vs 22.4% of non-Latinas), comorbidity, and poor-to-fair health (40.9% for Latinas vs. 32.8% for non-Latinas).

Table 2 shows the comparisons for outcome measures. Overall, Latinas were less satisfied with the

**TABLE 2.** Comparisons for Key Outcome Measures Among Latinas and Non-Latinas

	Non-Latinas N = 58		Latinas N = 154		P <sup>a</sup>
	Mean	SD	Mean	SD	
BC knowledge	30.7	5.1	27.3	5.0	<b>&lt;.0001</b>
Survivorship preparedness	42.7	8.8	41.0	8.4	.191
PEPPI	42.2	10.0	38.2	12.0	<b>.026</b>
BCPT symptoms	5.0	3.9	6.4	4.6	<b>.035</b>
Satisfaction with BC information received	3.4	1.2	2.3	1.1	<b>&lt;.0001</b>
Satisfaction with BC survivorship care	9.6	9.2	8.8	1.8	.298
Satisfaction with survivorship care discussion with physician	9.6	9.4	8.1	2.8	.077

Abbreviations: BC, breast carcinoma; BCPT, Breast Cancer Prevention Trial Symptom Checklist; PEPPI, Perceived Efficacy in Patient-Physician Interactions Questionnaire; SD, standard deviation.

<sup>a</sup>Bold type indicates statistical significance.

information they received for BC care compared with non-Latinas (2.3 vs 3.4;  $P < .0001$ ) and reported less BC survivorship knowledge (27.3 vs 30.7;  $P < .0001$ ). In addition, Latinas reported lower PEPPI scores (38.2 vs 42.2;  $P = .026$ ) and experienced more BCPT symptoms (6.4 vs 5.0;  $P = .035$ ) compared with non-Latinas. However, no differences were noted with regard to satisfaction with BC survivorship care, discussion with physicians, and their confidence in survivorship care preparedness.

The ethnic differences for outcome measures remained significant after adjusting for demographic and clinical characteristics, except for PEPPI (Table 3.)

## DISCUSSION

To our knowledge, the current study represents one of the few studies to date that have addressed BC survivorship disparities among the Latina population. Overall, not much is known regarding the factors that lead to disparities in this population.<sup>26-29</sup> In this light, the current study investigated levels of knowledge, preparedness, and satisfaction in the survivorship experience among Latinas diagnosed with BC and we posited that there are disparities therein.

Key findings after controlling for clinical and socio-demographic variables were that Latinas demonstrated less BC survivorship knowledge, reported more symptoms, and were less satisfied with the BC survivorship information they received when compared with non-Latinas. Nevertheless, they reported feeling as prepared for BC survivorship as non-Latinas and were equally satisfied with their health care providers.

Greater information giving has been associated with greater satisfaction and improved quality of life.<sup>14,30-32</sup> In one study, women with BC who had less knowledge regarding their condition reported regret about their treatment decisions.<sup>33</sup> This could be because they were unable

to share in decision making and depended solely on their physicians because they did not understand the information.<sup>34</sup> This is important because shared decision making, which is a function of knowledge level, leads to greater patient participation and treatment satisfaction, and is a predictor of improved quality of life.<sup>35,36</sup> Satisfaction with medical information also has been associated with improved physical and mental well-being.<sup>37</sup>

However, there is room for improvement in mitigating these barriers.<sup>38</sup> Culturally sensitive, linguistically appropriate health education and information sharing that acknowledges diversity (subgroups) in the Latina population is warranted.<sup>39-42</sup> Solutions that have been proffered include the use of Spanish-speaking health care providers<sup>39,43</sup>; simplification of information to an eighth-grade reading level or the use of a lay health advisor (the use of survivor-helper/peer-role model)<sup>44</sup>; and a 1-on-1 tailored approach in counseling,<sup>42,43</sup> as well as the training of practitioners in relevant communication skills.<sup>29,33,45</sup>

However, despite these disparities, the participants reported feeling as prepared for BC survivorship as non-Latinas and were as satisfied with their health care providers and with the discussions they had about survivorship care with their health care providers. However, the fact that Latinas demonstrated poorer BC survivorship knowledge may impede their ability to adhere to recommended survivorship care, which in turn could lead to poorer long-term health and quality of life outcomes, especially because they experienced greater BC-related symptoms. Adding to this concern is that Latinas appear to be at greater mortality risk after a diagnosis of BC compared with white women.<sup>46</sup> Perhaps interventions addressing improving BC survivorship knowledge among Latinas could impact their BC mortality.

Assessing satisfaction is pertinent because it can point to gaps in need and care.<sup>42,47</sup> Satisfaction with

**TABLE 3.** Adjusted Multiple Linear Regressions for Key Outcomes Using Hospital Plus Ethnicity Plus Demographics Plus Clinical Factors

	BC Knowledge			Survivorship Preparedness			PEPPI		
	Estimate	SE	P <sup>a</sup>	Estimate	SE	P <sup>a</sup>	Estimate	SE	P <sup>a</sup>
Harbor (reference group: LAC/USC)	-1.25	0.72	.084	0.79	1.14	.489	-0.32	1.49	.830
Latinas (yes)	-3.97	1.02	<b>.001</b>	-0.41	1.61	.799	-2.88	2.12	.176
Age	-0.01	0.04	.818	0.09	0.06	.130	-0.03	0.08	.752
High school graduate (yes)	-0.21	0.87	.805	-0.29	1.37	.830	0.51	1.80	.777
Employed (yes)	-0.46	0.79	.563	-4.14	1.24	<b>.001</b>	-4.91	1.64	<b>.003</b>
No. of comorbidities (1)	0.61	0.83	.462	1.50	1.30	.252	1.52	1.72	.376
No. of comorbidities (≥2)	-0.81	0.99	.416	-2.93	1.56	.062	-5.73	2.06	<b>.006</b>
SF-12 MCS	0.07	0.03	<b>.015</b>	0.23	0.04	<b>&lt;.0001</b>	0.27	0.06	<b>&lt;.0001</b>
SF-12 PCS	0.09	0.04	<b>.032</b>	0.13	0.07	.043	0.14	0.09	.120

	BCPT Symptoms			Satisfaction With BC Information Received			Satisfaction With BC Survivorship Care			Satisfaction With Survivorship Care Discussion With Physician		
	Estimate	SE	P <sup>a</sup>	Estimate	SE	P <sup>a</sup>	Estimate	SE	P <sup>a</sup>	Estimate	SE	P <sup>a</sup>
Harbor (reference group: LAC/USC)	1.07	0.46	<b>.022</b>	-0.01	0.15	.930	-0.15	0.74	.836	-0.01	0.78	.986
Latinas (yes)	1.99	0.66	<b>.003</b>	-1.16	0.22	<b>&lt;.0001</b>	-0.60	1.04	.568	-1.58	1.11	.155
Age	0.01	0.03	.667	-0.02	0.01	.068	0.09	0.04	<b>.020</b>	-0.10	0.04	<b>.025</b>
High school graduate (yes)	0.62	0.56	.267	0.01	0.18	.969	-0.12	0.89	.894	-0.69	0.94	.461
Employed (yes)	0.07	0.51	.888	-0.25	0.17	.144	-1.51	0.81	.062	-1.71	0.86	<b>.048</b>
No. of comorbidities (1)	0.24	0.53	.656	0.49	0.18	.006	-0.11	0.84	.894	-0.30	0.90	.740
No. of comorbidities (≥2)	-0.47	0.64	.459	0.01	0.21	.949	-0.86	1.01	.398	-1.15	1.07	.286
SF-12 MCS	-0.13	0.02	<b>&lt;.0001</b>	0.02	0.01	<b>&lt;.0001</b>	-0.02	0.03	.458	-0.01	0.03	.652
SF-12 PCS	-0.23	0.03	<b>&lt;.0001</b>	0.01	0.01	0.382	0.15	0.04	<b>.001</b>	0.17	0.05	<b>.001</b>

Abbreviations: BC, breast carcinoma; BCPT, Breast Cancer Prevention Trial Symptom Checklist; LAC, Los Angeles County; MCS, Mental Component Score; PCS, Physical Component Score; PEPPI, Perceived Efficacy in Patient-Physician Interactions Questionnaire; SE, standard error; SF-12, 12-item Short Form Health Survey; USC, University of Southern California.

<sup>a</sup> Bold type indicates statistical significance.

health care providers has been associated with the continued use of health care services, health care provider follow-up care, better psychological outcomes, and improved quality of life.<sup>36,40,42,46,48,49</sup> Better patient-physician communication is associated with self-efficacy, adherence, and satisfaction with care.<sup>30,31,50</sup>

Within the context of the current study, findings concerning satisfaction could reflect the fact that the sample was taken from 2 hospitals that are specifically designated to serve the underserved. Some studies have shown that satisfaction level may be overrated.<sup>42,51,52</sup> Another explanation is that satisfaction could be a function of spirituality and religiosity because these have been found to be central to recovery and coping throughout Latinas' experiences with cancer.<sup>10,53,54</sup> Some studies have shown that spirituality enhances satisfaction during their survivorship phase and leads to better relationships with their physicians.<sup>55,56</sup>

Nonetheless, certain limitations should be kept in mind when evaluating the current study results. This study was cross-sectional, thus limiting assertions of causality. In

addition, the possibility of response bias among the respondents cannot be ruled out and, more important, external generalizability to all Latina populations may be limited.<sup>57,58</sup>

Analysis of the current study sample of 212 survivors of BC who received care at 2 public county hospitals that serve the underserved in Los Angeles suggests that disparities exist in the survivorship needs and care of Latina survivors of BC compared with non-Latina, white survivors. However, more research is needed to generalize the current study findings beyond the study sample. In addition, longitudinal studies to investigate the role of such variables as competing life needs, work, and family responsibilities in preparedness and survivorship are warranted. Nonetheless, we believe the results of the current study are encouraging because many of the factors accounting for disparities are modifiable.

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## CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

## AUTHOR CONTRIBUTIONS

Conception and design: **Yihang Liu, Li-Jung Liang, Jennifer J. Griggs, Patricia A. Ganz, and Rose C. Maly.** Collection and assembly of data: **Yihang Liu, Li-Jung Liang, and Rose C. Maly.** Data analysis and interpretation: **All authors.** Article writing: **All authors.** Final approval of article: **All authors.** Accountable for all aspects of the work: **All authors.**

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