

Disparities in the Survivorship Experience among Latina Breast Cancer Survivors

Running Title: Latina "Breast Cancer Survivorship" Disparity

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### **Conflict of Interest**

Authors Tinuke O. Olagunju, Yihang Liu, Li-Jung Liang, James M. Stomber, Jennifer J Griggs, Patricia A. Ganz, Amardeep Thind, and Rose C. Maly declare no conflict of interest.

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Manuscript writing: All authors

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## ABSTRACT

*Purpose:* We 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 10-24 months after diagnosis of breast cancer (Stage 0-III) at two Los Angeles County public hospitals. Data were collected using 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, education, and study site in multivariate analyses.

*Results:* The mean ages of Latinas and non-Latinas were 51.5 and 56.6 years respectively. Compared to 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,  $P=0.03$ ) and experienced more BCPT symptoms (6.4 vs 5.0,  $P=0.04$ ). No differences existed regarding their confidence in survivorship care preparedness (42.7 vs 41,  $P=0.191$ ), satisfaction with BC survivorship care (9.6 vs 8.8,  $P=0.298$ ) or their discussion with physicians (9.6 vs 8.1,  $p=0.07$ ). These ethnic group differences persisted in multivariate analyses, except for PEPPI.

*Conclusions:* Latina BC survivors experienced disparities in BC knowledge and satisfaction with information received, but felt as prepared for survivorship, and satisfied with providers, care received and discussions with physicians as did non-Latinas.

## CONDENSED ABSTRACT

We investigated disparities in the survivorship experience among Latinas with breast cancer (BC) in comparison with non-Latinas. Latina BC survivors experienced disparities in BC knowledge and satisfaction with information received, but felt as prepared for survivorship, and satisfied with providers, care received and discussions with physicians as did non-Latinas.

Keywords: Breast Cancer, Disparity, Knowledge-Preparedness-Satisfaction, Latina, Survivorship

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## 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 breast cancer survivors is expected to grow dramatically given the expected increase in incidence of breast cancer and continued improvements in the detection and successful treatment of breast cancer. Patients who have had breast cancer experience impaired quality of life, bothersome symptoms, and clinical problems after treatment.<sup>2,3</sup> Many of these post-treatment issues may evade attention because of diminishing contact with cancer specialists after initial treatment is over; lack of expertise among primary care providers to deal with such side effects; lack of a standard protocol for follow-up after treatment, and non-specific guidelines for dealing with these issues.

Accordingly, women with breast cancer report a high need for information about cancer-related issues following treatment; needs that are largely unmet.<sup>4,5</sup> These challenges are often 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 less is known about 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>

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 in breast cancer treatment-related symptoms and health-related quality of life.<sup>12-14</sup> In a longitudinal study, breast cancer patients 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 is also 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>

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

## METHODS

### *1) Recruitment*

We conducted a baseline, cross-sectional survey to assess survivorship knowledge, preparedness and satisfaction among a low-income population of women with BC enrolled in a randomized controlled trial of survivorship care plans.<sup>17</sup> Participants were recruited from two breast clinics located in the Los Angeles area, Harbor-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 Los Angeles County. The study was approved by the institutional review boards of both county hospitals and UCLA.

Eligibility criteria used in the recruitment process were: English- or Spanish-speaking female, age of 21 years or older, with a diagnosis of ductal carcinoma in situ (DCIS) or Stage I, II, or III breast cancer for the first time within 10 and 24 months and at least one-month post chemotherapy. Exclusion criteria included: previous cancer (except non-melanomatous skin cancers or in situ (non-breast) cancers), pregnant and lactating women, patients currently receiving trastuzumab or other parenteral anti-cancer therapy, metastatic disease, clinically apparent cognitive or psychiatric

impairment, participation in another research study, currently being treated for another cancer, unwillingness to sign the medical record release form, or not living in Los Angeles County at the time of the study. Potential participants' contact information 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 two 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.

### *II) Questionnaire design and use*

All eligible participants completed a questionnaire to collect information regarding socio-demographics, co-morbidities, breast cancer 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 2) independent back translation into English 3) an independent conceptual equivalence rating of the back-translation and the source by a professional translator, a research assistant, and a lay person; and 4) modification or re-translation of items with low conceptual equivalence ratings. Translation was geared towards the Mexican-American subpopulation of Spanish-speaking residents of California as Census data showed that 75% of Hispanics in LA County are Mexican in origin.<sup>18</sup>

### *III) Measures*

Outcome variables: These included BC knowledge about survivorship issues, BC survivorship preparedness, patient perceived efficacy in patient-physician interactions, breast cancer-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 two-part Preparing for Life as a (New) Survivor (PLANS) Scale consisting of 11 items.<sup>19</sup>

*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 employed the Perceived Efficacy in Patient-Physician Interactions (PEPPI) Questionnaire using the 5-item version of the instrument, which has demonstrated a Cronbach's alpha of 0.91.<sup>20</sup>

*BCPT 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 BC survivors was employed 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 one-item question to ask 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 one-item question adapted from CAHPS. It asks survivors to rate how satisfied they were with the discussions with their physicians about their BC follow up care on a scale of 0-10, with 0 indicating not at all satisfied and 10 for very satisfied.

Independent variables: The key covariate of interest was ethnicity, which was self-reported. Control variables included patient socio-demographic 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> the Mental Component Score and the Physical Component Score from the 12-item Short Form Health Survey ( SF12 MCS and SF12 PCS, respectively).<sup>25</sup>

#### *IV) Data Analyses*

Descriptive measures, including means, counts and percentages as appropriate, were assessed. Chi-square tests and t-tests were used to compare demographic, clinical characteristics and key outcome measures between Latina and non-Latina BC survivors. Mixed-effects regression (PROC Mixed) models with hospital-level random effects were first used to assess ethnic differences on the outcome measures. We included the hospital-level random effect to account for potential correlations within hospitals. However, results showed that the G matrix was not positive definite; thus, the hospital-level random effect was removed. We then examined the ethnic differences adjusted for socio-demographic factors (age, education and employment) and clinical characteristics (comorbidity, SF12 MCS and SF12 PCS) using multiple linear regression, with hospital as a fixed effect. All statistical analyses were conducted using SAS, version 9.1; two-sided alpha levels with p values less than 0.05 were considered statistically significant.

## RESULTS

A total of 212 breast cancer survivors completed the baseline interview, 58 non-Latinas and 154 Latinas. The non-Latina group included 33 black, 10 white, 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 vs 56.6,  $P=0.0001$ ); were more likely to be partnered (57.8% vs 25.9%,  $P<.0001$ ) but less likely to have enough money to cover their needs, with about 95% of Latinas reporting an annual household income of less than \$30,000 (84.5% for non-Latinas,  $P=0.026$ ). Other demographic disparities include educational attainment, with 89.7% of the non-Latinas having a high school degree or more, whereas only 24.0% of the Latinas had a high school degree or more ( $P<.0001$ ).

In general, both groups reported lower scores than the SF-12 national general population norms for the mental health score (42.6 for Latinas and 45.5 for non-Latina) and the physical health score (41.0 for Latinas and 39.9 for non-Latina); 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, 22.4% of non-Latinas), co-morbidity and poor-fair health (40.9%; 32.8%).

Table 2 shows the comparisons for outcome measures. Overall, Latinas were less satisfied with the 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,  $P=0.026$ ) and experienced more BCPT symptoms (6.4 vs 5.0,  $P=0.035$ ) than non-Latinas. However, no differences existed regarding satisfaction with BC survivorship care, discussion with physicians and their confidence in survivorship care preparedness.

The ethnic differences for outcome measures stayed significant after adjusting for demographic and clinical characteristics except for PEPPi (see Table 3.)

## DISCUSSION

To our knowledge, this work represents one of the few that have addressed breast cancer survivorship disparities among the Latina population. Overall, not much is known about the factors that lead to disparities in this population.<sup>26-29</sup> In this light, our study investigated knowledge,

preparedness and satisfaction levels in the survivorship experience among Latinas diagnosed with breast cancer and we posited that there are disparities therein.

Key findings after controlling for clinical and socio-demographic variables were that the Latinas demonstrated less breast cancer survivorship knowledge, reported more symptoms, and were less satisfied with the breast cancer survivorship information they received when compared to non-Latinas. Yet, they reported feeling as prepared for breast cancer 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 about 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 as 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, treatment satisfaction, and is a predictor of improved quality of life.<sup>35, 36</sup>

Satisfaction with medical information has also been associated with improved physical and mental well-being.<sup>37</sup>

There is however, room for improvement in mitigating these barriers.<sup>38</sup> Culturally-sensitive linguistically appropriate health education and information sharing that acknowledges diversity (sub-groups) in the Latina population is warranted.<sup>39-42</sup> Solutions that have been proffered include the use of Spanish-speaking healthcare providers;<sup>39, 43</sup> simplification of information to eight-grade level readability/lay health advisor (the use of survivor-helper/peer-role model;<sup>44</sup> one-on-one tailored approach in counseling,<sup>42, 43</sup> as well as training of practitioners in relevant communication skills.<sup>29, 33,</sup>

Despite these disparities however, the participants reported feeling as prepared for breast cancer 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 since they experienced greater BC-related symptoms. Adding to this concern is that Latinas appear to be at greater mortality risk after breast cancer diagnosis than do Caucasians.<sup>46</sup> Perhaps interventions addressing improving BC survivorship knowledge among Latinas could impact on their BC mortality.

Assessing satisfaction is pertinent as it can point to gaps in need and care.<sup>42, 47</sup> Satisfaction with health care providers has been associated with continued use of health care services, health care providers 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>

In our context, findings on satisfaction could reflect the fact that the sample was taken from two 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 as these have been found to be central to recovery and coping throughout the 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 doctors.<sup>55, 56</sup>

Nonetheless, certain limitations should be kept in mind when evaluating our results. Our study was cross-sectional thus limiting assertions of causality, the possibility of response bias among the respondents cannot be ruled out, and more importantly, external generalizability to all Latina populations may be limited.<sup>57, 58</sup>

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

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#### Figure Legends

Figure 1: Study Flow Diagram

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

	<b>Latinas (N=154)</b>	<b>Non-Latinas (N=58)</b>	<b>P-value</b>
<b>Age (years)</b> Mean(SD), [Range]	51.5 (10.1)[29 -78]	56.6 (7.6) [37-85]	0.0001
<b>Education, N (%)</b> High school or greater	37 (24.0)	52 (89.7)	<.0001
<b>Income, N (%)</b> <\$30,000 \$30,000-\$49,999 \$50,000+	146 (94.8) 7 (4.6) 1 (0.7)	49 (84.5) 6 (10.3) 3 (5.2)	0.026
<b>Married/Partnered, N (%)</b> Yes	89 (57.8)	15 (25.9)	<.0001
<b>Employed, N (%)</b> Yes	45 (27.4)	13 (22.4)	0.322
<b>Comorbidity, N (%)</b> 1 2 and more	44 (28.6) 32 (20.8)	13 (22.4) 14 (24.1)	0.811
<b>Time since BC Diagnosis (months)</b> Mean(SD), [Range]	17.7 (5.1)	19.2 (5.5)	0.198
<b>General Health Status, N (%)</b> Poor/Fair	63 (40.9)	19 (32.8)	0.277
<b>Usual Source of Care, N (%)</b> Yes	134 (87.0)	48 (82.8)	0.428
<b>SF-12 Measures, Mean (SD)</b> SF-12 MCS SF-12 PCS	42.6 (13.2) 41.0 (9.2)	45.5 (12.7) 39.9 (9.1)	0.156 0.462

**Table 2. Comparison for key outcome measures among Latinas and non-Latinas**

	<b>Non-Latinas (N=58)</b>		<b>Latinas (N=154)</b>		<b>P value</b>
	Mean	Std Dev	Mean	Std Dev	
<b>BC knowledge</b>	30.7	5.1	27.3	5.0	<b>&lt;.0001</b>
<b>Survivorship preparedness</b>	42.7	8.8	41.0	8.4	0.191
<b>PEPPI</b>	42.2	10.0	38.2	12.0	<b>0.026</b>
<b>BCPT symptoms</b>	5.0	3.9	6.4	4.6	<b>0.035</b>
<b>Satisfaction with BC info received</b>	3.4	1.2	2.3	1.1	<b>&lt;.0001</b>
<b>Satisfaction with BC survivorship care</b>	9.6	9.2	8.8	1.8	0.298
<b>Satisfaction with survivorship care discussion with physician</b>	9.6	9.4	8.1	2.8	0.077

**Table 3: Adjusted Multiple Linear Regressions for Key Outcomes Using Hospital + Ethnicity + Demographics + Clinical Factors**

	BC knowledge			Survivorship preparedness			PEPPI		
	Estimate	SE <sup>3</sup>	P value	Estimate	SE <sup>3</sup>	P value	Estimate	SE <sup>3</sup>	P value
Harbor (reference group: LAC/USC)	-1.25	0.72	0.084	0.79	1.14	0.489	-0.32	1.49	0.830
Latinas (Yes)	-3.97	1.02	<b>0.001</b>	-0.41	1.61	0.799	-2.88	2.12	0.176
Age	-0.01	0.04	0.818	0.09	0.06	0.130	-0.03	0.08	0.752
High school graduated (Yes)	-0.21	0.87	0.805	-0.29	1.37	0.830	0.51	1.80	0.777
Employed (Yes)	-0.46	0.79	0.563	-4.14	1.24	<b>0.001</b>	-4.91	1.64	<b>0.003</b>
Comorbidity (1)	0.61	0.83	0.462	1.50	1.30	0.252	1.52	1.72	0.376
Comorbidity (2 or more)	-0.81	0.99	0.416	-2.93	1.56	0.062	-5.73	2.06	<b>0.006</b>
SF12 MCS	0.07	0.03	<b>0.015</b>	0.23	0.04	<b>&lt;.0001</b>	0.27	0.06	<b>&lt;.0001</b>
SF12 PCS	0.09	0.04	<b>0.032</b>	0.13	0.07	0.043	0.14	0.09	0.120

	BCPT symptoms			Satisfaction with BC info received			Satisfaction with BC survivorship care			Satisfaction with survivorship care discussion with physician		
	Estimate	SE <sup>3</sup>	P value	Estimate	SE <sup>3</sup>	P value	Estimate	SE <sup>3</sup>	P value	Estimate	SE <sup>3</sup>	P value
Harbor (reference	1.07	0.46	<b>0.02</b>	-0.15	0.15	0.93	-0.74	0.83	0.98	-0.78	0.98	0.98

group: LAC/USC)			<b>2</b>	0.01		0	0.15		6	0.01		6
Latinas (Yes)	1.99	0.66	<b>0.003</b>	-1.16	0.22	<b>&lt;.0001</b>	-0.60	1.04	0.568	-1.58	1.11	0.155
Age	0.01	0.03	0.667	-0.02	0.01	0.068	0.09	0.04	<b>0.020</b>	0.10	0.04	<b>0.025</b>
High school graduated (Yes)	0.62	0.56	0.267	0.01	0.18	0.969	-0.12	0.89	0.894	-0.69	0.94	0.461
Employed (Yes)	0.07	0.51	0.888	-0.25	0.17	0.144	-1.51	0.81	0.062	-1.71	0.86	<b>0.048</b>
Comorbidity (1)	0.24	0.53	0.656	0.49	0.18	0.006	-0.11	0.84	0.894	-0.30	0.90	0.740
Comorbidity (2 or more)	-0.47	0.64	0.459	0.01	0.21	0.949	-0.86	1.01	0.398	-1.15	1.07	0.286
SF12 MCS	-0.13	0.02	<b>&lt;.0001</b>	0.02	0.01	<b>&lt;.0001</b>	-0.02	0.03	0.458	-0.01	0.03	0.652
SF12 PCS	-0.23	0.03	<b>&lt;.0001</b>	0.01	0.01	0.382	0.15	0.04	<b>0.001</b>	0.17	0.05	<b>0.001</b>

SE : Standard Error

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Study Flow Diagram – Figure 1

