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## A Community-Based Approach to Assessing the Physical, Emotional, and Health Status of Hispanic Breast Cancer Survivors

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### Abstract

**Introduction**—Latina breast cancer survivors in the United States face disproportionate risk for poorer quality of life and physical health, as well as greater emotional distress.

**Method**—A cross-sectional survey was conducted to describe the physical, emotional, and general health status of 135 Latina breast cancer survivors served by a community-based program.

**Results**—Of the 135 surveys sent, 48 survivors responded. Of those who responded, time since diagnosis ranged from 0 to 24 years ( $M = 4.37$ ;  $SD = 5.54$ ); and 45.9% of the women rated physical health as poor or fair. Fatigue prevalence was high, with 60.5% reporting fatigue as moderate or severe. Nearly 80% reported having pain (score >0); 38.3% reported pain was moderate or severe. The women reported mild levels of anxiety and depression but high levels of stress ( $M = 4.14$ ;  $SD = 3.02$ ).

**Conclusions**—Latina breast cancer survivors could benefit from interventions focused on commonly shared problems while tailoring specific interventions for subsets with more severe symptoms.

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## Keywords

breast cancer; community-based participatory research; health disparities; Latino populations; vulnerable populations; community health

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## Introduction

The number of cancer survivors in the United States is currently estimated at over 14 million and is expected to increase significantly (American Cancer Society, 2015). Breast cancer is the most common form of cancer among Hispanic/Latina women and is often detected at an advanced stage (Scheel et al., 2017). Cancer and its related treatment side effects can cause short- and long-term quality of life health concerns for all women. These concerns are aggravated for Hispanic/Latina women, who, compared with their non-Hispanic counterparts, have additional socioeconomic, cultural, and psychosocial burdens, which produce increased vulnerabilities to poorer quality of life and more challenging survivorship outcomes (Juarez, Hurria, Uman, & Ferrel, 2013). Barriers to health care—due to poverty, lack of insurance, limited English proficiency, lack of understanding of the disease and treatments, or discrimination—can lead to greater physical and emotional distress, resulting in poorer overall health status (Martinez-Ramos, Biggs, & Lozano, 2013).

Evidence to date indicates that mental or emotional functioning (fear, anxiety, distress, and depressive symptoms) and physical quality of life concerns are worse for Latina breast cancer survivors than for women of other racial/ethnic groups (Juarez, Mayorga, Hurria, & Ferrel, 2013). Yanez, Thompson, and Stanton (2011) conducted an extensive systematic review exploring the concept of quality of life and physical, mental, social, and sexual concerns among breast cancer survivors. Their findings concluded that Latina breast cancer survivors experienced greater depressive symptoms and a significantly lower quality of life than women of other races/ethnicities. In a review of interventions developed and implemented to support Latinas through their breast cancer trajectory, Molina, Thompson, Espinoza, and Ceballos (2013) reported that Latinas experience greater anxiety, fear, and depression and poorer quality of life than their non-Hispanic counterparts.

In response to these inequities and increased risks for poorer physical and mental health among Latina survivors of breast cancer, a cross-sectional study was conducted. This study aimed to examine the physical, emotional, and general health status of Latina breast cancer survivors attending a local cancer education and support group. Research questions included the following: (1) What is the emotional, physical, and health status of Latina women attending a long-standing, monthly community support group? (2) To what extent are selected clinical variables (comorbidities, body mass index [BMI], stage of cancer, time since diagnosis) associated with emotional and physical health status? Because emotional distress was of great concern for community partners, the following question was included: (3) What instruments are most useful (in terms of complete data and variance) in measuring emotional distress among this group of Latina breast cancer survivors?

## Method

In this study, a community-based participatory research team collaborated to enhance services to Latinas suffering with breast cancer in a large community in the Midwest. A community-based participatory research approach allows nurses to work together with members of the community to engage complex and multifaceted health concerns in a culturally sensitive manner. The research team consisted of bilingual nurse scientists, Latina breast cancer survivors, patient navigators, and community stakeholders; for 2 years this team has been working together to assess the needs of this community. Using a socioecological perspective, which takes into account social and environmental factors that affect health and well-being, a survey was developed and conducted to examine the current emotional, physical, and health status of this group of Latinas with breast cancer.

## Sample

The sampling frame included 135 active members who were breast cancer survivors and who were receiving community-based services from the Alliance Community Services Breast Cancer (ABC) Program. Most members ( $n = 125$ ) were identified through a database maintained since the program began in 2002. An additional 10 received the survey at a support group meeting. All participants spoke Spanish and preferred to be interviewed in Spanish. Inclusion criteria included the following: Hispanic women with a diagnosis of breast cancer, adult (21 or over), Spanish-speaking, and actively attending the support group. Exclusion criteria included anyone who was emotionally or physically not able to participate in the study. The ABC Program is offered by Alliance Community Services, a community nonprofit organization founded in 2002 to provide social and preventive health services to Hispanics/Latinos in Utah. The program is innovative in providing services to women across the cancer continuum and includes health education and screening, cancer detection and follow-up, and supportive care for long-term breast cancer survivors (Sanchez-Birkhead, Carbajal-Salisbury, Larreta-Arce, Hendricks, & Beck, 2016). Services for breast cancer survivors include *Novedades*, a monthly newsletter; *Triunfadoras*, the only psychoeducational support group for Hispanic breast cancer survivors in the community; and *Entre Amigas*, a peer-to-peer at-home visit program. The study was approved by the institutional review board at the University of Utah.

## Measures

The researchers identified and reviewed potential measures of the constructs of interest that had been previously tested in Spanish. Unsure about the best approach to measuring emotional distress in this population, the research team decided to test several different approaches, as described below.

**Demographic data collection sheet**—A Demographic Data Collection Sheet was developed, which was translated into Spanish by two native, bilingual, bicultural Latina women. This tool included items such as age, marital status, education, income, time in the United States, region of origin, and insurance status.

**Emotional thermometer**—The Emotional Thermometer tool (Mitchell, Baker-Glenn, Granger, & Symonds, 2010) was adapted for this study. The original tool included four graphics of specific emotional thermometers (stress, anxiety, anger, and depression) and one outcome measure (need for help). Each thermometer was rated on a 0 to 10 numeric scale with 0 being *nada* (none) and 10 being *Demasiado* (Too much). Mitchell et al. (2010) tested the thermometers in 130 cancer patients and found support for construct validity as compared with other measures of emotions (the Hospital Anxiety and Depression Scale and the *DMS-IV* Major Depression). They concluded that specific emotional thermometers augment the data in the distress thermometer by capturing more specific types of emotions. Input from community members led the research team to expand the tool and add a thermometer for panic. Each response was analyzed as a single item variable; there was no scale score.

**PROMIS global health scale**—The PROMIS Global Health Scale is a 10-item measure that captures physical, mental, and social aspects of health-related quality of life (Cella et al., 2010). Seven items capture health status in general and three assess symptoms over the past 7 days. Nine items use 5-point categorical ordered scales; the pain item uses the widely accepted 0 to 10 numeric scale. Scoring algorithms convert responses to standardized *t* scores for physical and mental health status (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). *T* scores provide a standardized measure in which a score of 50 represents the population mean and a difference of 10 from the mean indicates a difference of one standard deviation.

**My own health report**—Four items to measure emotional status were included in the My Own Health Report (MOHR) health risk assessment tool. Evidence supports the tool as brief, reliable, valid, and actionable (Glasgow, Kaplan, Ockene, Fisher, & Emmons, 2012). Eliciting categorical, ordinal responses, the four items measure the frequency that emotions were experienced within the past 2 weeks.

**Short acculturation scale for Hispanics**—The 4-item Short Acculturation Scale for Hispanics was used to measure participants' level of acculturation (Marin, Sabogol, Marin, Otero-Sabogal, & Perez-Stable, 1987). This brief version estimates acculturation based on the participants' language preference (Spanish or English) in various settings.

## Procedure

Women were informed about the study through an announcement at the monthly support group meeting and a notice in their *Novedades* monthly newsletter. One hundred twenty-five survey packets were mailed with postage-paid return envelopes; 10 more were distributed at monthly support group meetings. Women were advised that return of the survey implied consent to voluntarily participate. Participants received two reminder and encouragement phone calls from support group staff regarding the mail-in surveys. Participants received a \$5 gift card to a local grocery store for returning a completed survey.

## Analysis

All data were analyzed using SPSS version 21. Descriptive statistics (frequencies, percentages, means, medians, standard deviations) was conducted. Bivariate correlations were used to examine associations between selected demographic or clinical variables and the women's current health status.

## Results

Forty-eight of 135 surveys were returned for a 35.5% response rate. The demographic characteristics are summarized in Table 1. The women ranged in age from 35 to 74 years, with a mean age of 52.6 years. All the women self-identified as Hispanic, and although they were asked about race, no additional categories were selected. The majority were married (58.3%). The countries of origin varied, with over half coming from Mexico. Income and education also varied; 60.4% worked outside the home. Only 50% reported having health insurance. Time in the United States varied from 1 to 30 years ( $M = 16.02$ ;  $SD = 6.43$ ). Almost half of respondents (47.9%) scored a 4 (lowest possible) on the Short Acculturation Scale for Hispanics.

### Emotional and Physical Health Status

Table 2 summarizes the findings for measures of emotional and physical symptoms and health status. The PROMIS Global Scale yielded the most complete data; the Mental Health Subscale mean score was 46.08 ( $t$  score). The emotional thermometers indicated that on average the women reported mild levels of anxiety, depression, anger, and panic; the exception was the stress thermometer, which had the highest mean ( $M = 4.14$ ;  $SD = 3.02$ ). Measures of emotional status from the MOHR Screening questions indicated that the majority had no anxiety or depression. Depending on the measure, there was a subset of up to 10 women (21.3%) who indicated a level of emotional distress that would likely warrant intervention, although many women experienced emotional distress some of the time.

In terms of physical health, 45.9% rated this item as poor or fair. The mean score for the Physical Health Subscale of the PROMIS tool was 44.09 ( $t$  score). There was a high prevalence of fatigue, with 60.5% reporting symptoms that were moderate or severe. Nearly 80% reported having pain (score  $>0$ ); for 38.3% of the women, the level was 4 or higher, indicating at least a moderate level of pain.

### Correlates of Health Status

The number of comorbidities ranged from 0 to 5 with a median of 1; two thirds of respondents reported one or more comorbid conditions. Number of comorbidities was negatively correlated with the PROMIS Physical Health status score ( $r = -.42$ ;  $p = .004$ ) and pain ( $r = -.36$ ,  $p = .017$ ). Only 70% of the women knew the stage of their breast cancer. Of these, 35.3% were Stage 0 to 1, and 64.7% were Stage 2 or 3. Cancer stage was not significantly correlated with physical or mental health. The mean BMI ( $n = 39$ ) was 29.03 ( $SD = 7.01$ ). Of women who responded to the weight question, 30.76% were overweight and 41.02% were obese. BMI was significantly correlated with physical health status ( $r = .345$ ,  $p = .034$ ). Time since diagnosis ranged from 0 to 24 years; the mean was 4.37 years ( $SD =$

5.54); 28.3% were diagnosed within the past year and 29.3% were diagnosed 5 or more years ago. Time since diagnosis was positively correlated with comorbidities ( $r = .65, p < .001$ ) and pain ( $r = .38, p = .01$ ).

## Discussion

In this study, physical, emotional, and general health outcomes of Latina breast cancer survivors receiving supportive services through a community-based program were explored. Additionally, multiple approaches to assess emotional distress in an effort to inform a future intervention study was examined. Consistent with other research on breast cancer survivors, the findings in this study indicate that women continue to experience health challenges, such as fatigue and pain and described their physical health as poor to fair (Bower, 2008; Eversley et al., 2005; Graves et al., 2014; Howard-Anderson, Ganz, Bower, & Stanton, 2012; Kiecolt-Glaser et al., 2014; Schubart et al., 2014). The percentage of women who rated their overall health as poor or fair was higher in this sample as compared with a national sample of breast cancer survivors (37.5%, vs. 27.5% in Yabroff, Lawrence, Clauser, Davis, & Brown, 2004).

Participants completed three different instruments that measure emotional distress. The PROMIS Global Health measure had the least amount of missing data; all items but one were completed by 100% of the women. This measure was included as it has the advantage of also measuring physical and social health status and overall health and comparability with other samples. The disadvantage is that emotional distress is measured in combination and specific types of emotions (e.g., depression and anxiety) are not distinguished. The MOHR provides distinct measures of depression and anxiety, and the Emotional Thermometers add stress, anger, and panic. The MOHR measures were placed first and some items had greater than 10% item nonresponse. All thermometers had more than 10% item nonresponse, with the “panic” thermometer exceeding 20%. Order of survey placement may have affected responses as the thermometers were placed later. The women reported increased risk factors affecting their physical health status. The percentage who were overweight and obese (71.8%) was much higher than in a national, population-based sample of cancer survivors (57.9%; Yabroff et al., 2004). The percentage having at least one comorbidity (63%) was also higher than in the breast cancer sample from that comparison study (56.3%; in Yabroff et al., 2004). Similar to other studies, over half of the women reported moderate or severe fatigue, and over one third reported moderate to severe pain (see Fu et al., 2009). In addition, 21.3% of women in this study indicated emotional distress warranting intervention. *T* scores on the PROMIS physical subscale were similar ( $t = 44.09$ ) to scores from a recent report of the PROMIS PF-16 in Hispanic cancer survivors with multiple diagnoses ( $t = 43.5$ ), and a little better than the Hispanic breast cancer sample in that same study ( $t = 41.5$ ; in Jensen et al., 2015). Interestingly, a low level of acculturation remained, even though most women had been in the United States for many years. The measure of acculturation was limited to questions about language, which, although widely used, is based on a restricted view of acculturation.

The findings in this study support the need to target interventions tailored to meet specific individuals' needs. For example, stress was the highest scored emotional measure overall and was moderate on average. Since stress is a common life experience regardless of breast

cancer status, including general stress management skills is recommended as an overall strategy for all survivorship programs. As fatigue and obesity were also prevalent, fatigue management education, nutrition counseling, physical activity, and lifestyle interventions to improve the women's overall functioning and general health status are recommended (Ligibel, 2011). However, there was more variation in reports of pain, depression, and anxiety. The findings in this study indicate that there is clearly a subset of survivors who could benefit from interventions targeting these issues. In addition, as two thirds of the women reported one or more comorbid conditions, integrating condition-specific self-management strategies could affect overall health status throughout survivorship. A system of regular screening assessments to triage women into a culturally tailored intervention program would provide a more individualized and patient-centered approach.

The relatively small sample size is a limitation of this study. Initially, community partners were skeptical regarding the survivors' ability to complete a mailed survey without assistance. Though assistance was offered, the majority of surveys received were completed independently and returned by mail. The response rate indicated that the survey approach was indeed feasible but perhaps not the best method for this population. Participants received reminder and encouragement phone calls from support group staff regarding the mail-in surveys. With additional resources, the use of more systematic approaches such as those outlined in the guiding principles by Dillman, Smyth, and Christian (2009) may improve response rates and limit bias. It is possible that non-respondents had lower literacy, did not understand the various tools, and were reluctant to request help. These factors, as well as order of survey tools, may have influenced the level of item nonresponse, particularly for the Emotional Thermometer. To increase response rates, future investigations should include more active strategies—perhaps multiple mailings, a phone survey option, or providing individual assistance in completing the survey materials.

## Conclusion

The findings of this study are relevant to other community support groups and programs that offer solely social support and educational interventions. Although the women receive critical cancer-related education by health professionals and peer-related social support from the ABC program, more attention is warranted in assessing and assisting survivors with their quality of life, physical, and emotional needs. Mental health counseling and primary care providers trained in post-cancer treatment care and survivorship concerns are critical needs for Hispanic breast cancer survivors as well as other groups of minority women. The fact that only half of the women had any type of health insurance and nearly all indicated very low acculturation levels is of great concern not only for the survivors but also for health care providers and community stakeholders, as well as local and state leaders.

Surveys such as these can help inform both the design and evaluation of supportive care programs for Hispanic/Latina breast cancer survivors. Effective, culturally tailored survivors-hip programs can help Hispanic breast cancer survivors to access appropriate care, thus improving overall health outcomes. Cancer-related education should be included in the development of interventions with Hispanic/Latina populations experiencing low levels of acculturation. In addition, survivor-ship interventions that address certain broadly

experienced problems, while providing opportunities to identify other issues relevant to a specific subset, will facilitate a more tailored, personalized approach. These study findings support developing foundational educational interventions focused on self-management of stress, fatigue, diet, and physical activity, as well as targeted interventions for subsets of women experiencing pain, depression, and anxiety.

As breast cancer survivors complete active treatment, they typically return to primary care settings with little to no cancer-specific support. This gap in the cancer care continuum demonstrates a great need for community-based programs, especially for vulnerable populations. Despite the prevalence of distressing symptoms throughout survivorship, studies indicate these symptoms are often underreported and undertreated. For instance, in a study focused on cancer-related fatigue, 74% of the patients believed fatigue was a symptom to be endured and only half had discussed treatment options with their physicians, indicating patients may consider these symptoms inevitable consequences of cancer treatment (Bower, 2008). These findings underscore the need to directly screen breast cancer survivors for distressing symptoms such as fatigue at each health visit, no matter the length of time since active treatment. Nurses can integrate simple screening questions focused on fatigue, pain, depression, and other behavioral symptoms.

Finally, through a community-engaged or participatory research approach, nurses and nurse scientists can partner with community members and stakeholders to develop culturally sensitive cancer self-management survivorship programs. Community-based participatory research teams can contribute to the development of research questions, study designs, program development, and interpretation of findings, as well as the dissemination of findings to community stakeholders and the academic and scientific communities. These community-based participatory research partnerships can heighten community ownership, enhance sustainability, and reduce disparities.

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**Table 1**Demographic Characteristics of Survey Respondents ( $n = 48$ ).

Characteristic	Mean (SD)	Range
Age (years)	52.60 (8.44)	35–74
Time in the United States (years)	16.02 (6.43)	1–30
Number of children	2.89 (2.10)	0–14
Acculturation Scale SF (4 items) <sup>a</sup>	5.98 (2.68)	4–17
Characteristic	Number	%
Country of origin		
Mexico	28	58.3
Peru	7	14.6
Guatemala	6	12.5
Columbia	2	4.2
Brazil	1	2.1
Chile	1	2.1
Ecuador	1	2.1
El Salvador	1	2.1
Uruguay	1	2.1
Region of origin—Parents		
Mexico	27	56.3
Central America	7	14.6
South America	13	27.0
USA	1	2.1
Marital status		
Married	28	58.3
Single/never married	6	12.5
Lives with a partner	3	6.3
Divorced	9	18.8
Widowed	1	2.1
No response	1	2.1
Education		
Elementary (1–6)	13	27.1
Middle school (7–9)	8	17.0
High school (10–12)	13	27.7
Some college (>12)	13	27.7
No response	1	2.1
Income		
Less than \$5,000	5	10.4
\$5,000–9,999	5	10.4
\$10,000–19,999	8	16.7
\$20,000–39,999	10	20.8

Characteristic	Mean (SD)	Range
More than \$40,000	2	6.3
Don't know	9	20.0
No response	8	16.7
Type of insurance		
Private	15	31.3
Medicare	5	10.4
Medicaid	3	6.3
Not specified	1	2.1
None	21	43.8
No response	3	6.3
Frequency of attending in the last year		
12 times	4	8.3
8–11 times	4	8.3
4–7 times	11	22.9
1–3 times	16	33.3
Never	12	25.0
No response	1	2.1

<sup>a</sup>Acculturation Scale ranges from 4 (*low*) to 20 (*high*).

**Table 2**

Frequencies, Means, and Standard Deviations of Emotional and Physical Symptoms.

<b>Emotional Thermometers<sup>a</sup> (n)</b>	<b>Mean (SD)</b>	<b>Range</b>
Stress (44)	4.14 (3.02)	0–10
Anxiety (39)	2.92 (2.92)	0–8
Depression (40)	2.65 (2.67)	0–9
Anger (40)	2.87 (2.83)	0–10
Panic (37)	1.65 (2.25)	0–8
Need for emotional help (40)	2.48 (2.99)	0–10
Level of pain <sup>b</sup> (47)	2.87 (2.26)	0–8
<hr/>		
<b>“My Own Health Report” Emotional Health Screening Items (n)</b>	<b>Number (Valid %)</b>	<b>Mean (SD)</b>
<hr/>		
Feeling nervous, anxious or on edge (44)		1.59 (0.87)
Not at all	26 (59.1)	
Several days	13 (29.5)	
More days than not	2 (4.5)	
Nearly every day	3 (6.8)	
Not being able to stop or control worrying (40)		1.78 (0.92)
Not at all	21 (51.2)	
Several days	13 (31.7)	
More days than not	4 (10)	
Nearly every day	3 (7.5)	
Feeling sad, depressed or without hope (41)		1.68 (0.82)
Not at all	21 (51.2)	
Several days	13 (31.7)	
More days than not	6 (14.6)	
Nearly every day	1 (2.4)	
Little interest or pleasure in doing things (42)		1.64 (0.82)
Not at all	22 (52.4)	
Several days	15 (35.7)	
More days than not	3 (7.1)	
Nearly every day	2 (4.8)	
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<b>PROMIS Global 10 Items</b>	<b>Number (Valid %)</b>	<b>Mean (SD)</b>
<hr/>		
In general, level of health (48)		2.81(0.89)
Excellent	2 (4.2)	
Very good	7 (14.6)	
Good	21 (43.8)	
Fair	16 (33.3)	
Poor	2 (4.2)	
Quality of life (48)		2.88 (0.70)
Excellent	1 (2.1)	

Emotional Thermometers <sup>d</sup> (n)	Mean (SD)	Range
Very good	6 (12.50)	
Good	27 (56.3)	
Fair	14 (29.2)	
Poor	0	
Level of physical health (48)		2.69 (0.88)
Excellent	2 (4.2)	
Very good	5 (10.4)	
Good	19 (39.6)	
Fair	20 (41.7)	
Poor	2 (4.2)	
Level of mental health (47)		3.19 (0.90)
Excellent	5 (10.4)	
Very good	9 (10.6)	
Good	23 (48.9)	
Fair	10 (21.3)	
Poor	0	
Satisfaction with social activities and relationships (47)		3.45 (0.80)
Excellent	3 (6.4)	
Very good	21 (44.7)	
Good	17 (36.2)	
Fair	6 (12.7)	
Poor	0	
Ability to carry out social activities and roles (48)		3.40 (0.77)
Excellent	4 (8.3)	
Very good	14 (31.3)	
Good	25 (52.1)	
Fair	4 (8.3)	
Poor	0	
Ability to carry out daily physical activities (48)		3.77 (0.95)
Completely	14 (29.2)	
Mostly	12 (25.0)	
Moderately	19 (39.6)	
A little	3 (6.3)	
Very little	0	
Affected by emotional problems like feeling anxious, depressed, or irritable (47)		2.51 (0.93)
Never	8 (17.0)	
Rarely	13 (27.7)	
Sometimes	20 (42.6)	
Often	6 (12.5)	
Always	0	
Level of fatigue (48)		2.71 (0.82)
None	3 (6.3)	

Emotional Thermometers <sup>a</sup> (n)	Mean (SD)	Range
Mild	16 (33.3)	
Moderate	21 (43.8)	
Severe	8 (16.7)	
Very severe	0	

<sup>a,b</sup> Emotional Thermometer and Level of Pain scales ranged from 0 (*None*) to 10 (*Highest*).

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