

Racial/Ethnic Differences in Adequacy of Information and Support for Women With Breast Cancer

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BACKGROUND. Providing breast cancer patients with needed information and support is an essential component of quality care. This study investigated racial/ethnic variations in the information received and in the availability of peer support.

METHODS. In total, 1766 women who were diagnosed with nonmetastatic breast cancer and reported to the Los Angeles County Surveillance, Epidemiology, and End Results registry from June 2005 to May 2006 were mailed a survey after initial treatment. Among accrued cases, 96.2% met eligibility criteria ($n = 1698$), and 72% completed the survey. Race/ethnicity categories were white, African American, and Latinas (2 categories indicating low or high acculturation, which was determined by using the Short Acculturation Scale for Hispanics). Outcomes included receipt and need for treatment-related and survivorship-related information, difficulty understanding information, and support from women with breast cancer.

RESULTS. More women reported receiving treatment-related information than survivorship-related information. After adjusting for sociodemographic, clinical, and treatment factors, a higher percentage of low acculturated Latina women desired more information on treatment-related and survivorship-related issues ($P < .001$). Significantly more Latina low acculturated women than white women reported difficulty understanding written materials, with 74.5% requiring help from others. A higher percentage of all minority groups compared with whites reported no contact with other women with breast cancer ($P < .05$) and reported less contact through family/friends ($P < .05$). Women rated the benefit of talking to other women high, particularly with emotional issues.

CONCLUSIONS. Continued efforts to provide culturally appropriate information and support needs to women with breast cancer are necessary to achieve quality care. Latinas with low acculturation reported more unmet information and care support needs than women in other racial/ethnic groups. *Cancer* 2008;113:1058-67. © 2008 American Cancer Society.

KEYWORDS: breast cancer, patient information, peer support, SEER, racial/ethnic differences.

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Informing patients with cancer about treatment and survivorship issues is a key component of quality of care. The relation between satisfaction with information received and quality-of-life outcomes in breast cancer has been documented in previous research.¹⁻⁴ Difficulty in accessing needed information can have a negative impact on emotional, functional, and social well being,¹ vitality,² and coping with the diagnosis.⁵ In addition, patients who are satisfied with the information they receive are more likely to comply with medical recommendations and treatments,^{1,6} and they have better communication with family members.⁷ Although the mechanisms by which information impacts health outcomes after breast cancer requires further study, some suggest that information may enhance a woman's perception of competence in dealing with her illness.¹

A growing body of literature has described the information and support needs for women after a breast cancer diagnosis.^{2,8,9} Most studies have focused on information needs during the diagnosis and treatment phase,⁹ and there has been less emphasis on information needs during survivorship.^{2,10} A number of studies have concluded that women with breast cancer often are dissatisfied with the extent to which their information needs are addressed, in terms of both the content and the source of delivery.^{1,8,10,11} There is some evidence that physicians provide less informational support to minority women with breast cancer.^{12,13} For the most part, however, the current literature is limited by a paucity of studies with adequate minority representation.^{1,2,9}

Although most women prefer to receive their cancer-related information from healthcare providers,^{12,14} other interpersonal sources, such as professionally led or peer-led support groups and 1-on-1 contact with other women who have had breast cancer, can augment the information provided by health professionals.⁹ Although some studies have indicated that there is less access to and less use of support groups among racial/ethnic minority survivors compared with whites,¹⁵⁻¹⁷ patients' wishes for more peer support opportunities have not been investigated adequately in most studies. To address gaps in the literature concerning racial/ethnic differences in information and support needs of women with breast cancer, we used a large, diverse population-based sample of women with breast cancer to answer the following 3 questions: 1) Do treatment and survivorship information needs differ by race/ethnicity? 2) Are there racial/ethnic differences in perceived difficulty understanding information? 3) Does support

received from other women with breast cancer differ by race/ethnicity?

MATERIALS AND METHODS

Study Population

Los Angeles County resident women ages 20 to 79 years who were diagnosed with primary ductal carcinoma in situ (DCIS) or invasive breast cancer (stage I-III) from June 2005 through May 2006 were eligible for sample selection for this study. Women were excluded if they could not complete a questionnaire in English or Spanish. Latina and African-American patients were over sampled.

Sampling and Data Collection

Patients were selected shortly after diagnosis as they were reported to the Los Angeles Cancer Surveillance Program, which is the Surveillance, Epidemiology, and End Results (SEER) cancer registry for Los Angeles County. This method of selection can yield a sample representative of the county population. We selected all African-American women based on demographic information from the treating hospitals. Because Latina status is not collected accurately by the treating hospital at the time of diagnosis, we used an alternative sampling strategy to increase the representation of Latina women in the study. We selected all women who were 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 U.S. Census.¹⁸ Then, we selected an approximately 11% random sample of the remaining white (non-Spanish surnamed) patients. Asian women were excluded, because these women already were being enrolled in other studies.

Physicians were notified of our intent to contact patients followed by the mailing of an introductory letter, survey materials, and a \$10 cash gift to participants. The patient survey was translated into Spanish using a standard approach.¹⁹ All patients who were likely to be Latina based on hospital or surname-based census information were sent bilingual materials. The Dillman survey method was employed to encourage response.²⁰ The study protocol was approved by the institutional review boards of the University of Michigan and the University of Southern California. The research followed established protocols of the SEER registries in Los Angeles for population-based research.

Over the study period, 1766 eligible patients were accrued, including 796 Latinas (based on the registry's Hispanic variable), 459 African Americans, 478 whites, and 33 patients with other racial cate-

gories. The accrued sample included approximately two-thirds of the Latina and African-American patients and 14% of the non-Latina white patients diagnosed with breast cancer in Los Angeles County during the study period. After initial patient contact, another 68 patients were excluded because 1) a physician refused permission to contact (7 women), 2) the patient did not speak English or Spanish (8 women), 3) the patient was too ill to participate (30 women), or 4) the patient denied having cancer (23 women). Of the 1698 patients who were included in the final accrued sample, 179 women (10.5%) could not be located or contacted, and 296 women (17.5%) who were located and contacted did not participate in the survey. Thus, a final sample of 1224 women (72%) completed the survey (97.8% of those women completed a written survey, and 2.2% completed a complete telephone survey).

Information from the survey was merged to SEER data for all patients in the final sample. An analysis of nonrespondents versus respondents indicated that there were no significant differences by age at diagnosis, race, or Hispanic ethnicity. However, compared with respondents, nonrespondents were less likely to have ever married (18.9% vs 25.2%; $P = .005$), were more likely to live in lower socioeconomic census tracts (48.6% vs 40.2%; $P = .030$), were more likely to have stage II or III disease (45.7% vs 40.3%; $P < .001$), and were less likely to have received breast-conserving surgery (56% vs 64.4%; $P < .001$).

Measures

Information needs

To determine the information needs of women with breast cancer, study participants completed a series of questions addressing receipt of and desire for more information on treatment and survivorship-related issues. The survey included 3 treatment-related items (managing recovery after surgery, side effects of radiation, and side effects of chemotherapy) and 4 survivorship-related issues items (effects of breast cancer/treatment on nutrition and/or diet, sexual function, relationships with spouse/partner, and feelings of anxiety/depression). For each item, respondents indicated whether they had received the information and whether they would have liked more information from physicians or their staff. The items relating to radiation and chemotherapy were restricted to those women who received the treatment in question. Additional items assessed whether women had difficulty understanding information (yes/no), needed someone else to help read written materials (yes/no), and knew who to ask questions regarding the material (yes/no).

Peer support opportunities

Respondents were asked to indicate whether or not they talked with other women who had breast cancer and, if so, whether a physician or staff member made the arrangements, whether they joined a support group, or whether they talked with a family member or friend who had breast cancer. In addition, women who reported that they talked with other breast cancer peers were asked to endorse various positive and/or negative consequences of the exchange, including whether talking 1) helped make treatment decisions, 2) helped emotionally, 3) made them doubt their treatment decisions, 4) helped them to know what to expect, 5) made them scared or anxious about treatment, 6) helped them to cope with the challenges and side effects of treatment, or 7) wonder why they did not get the same treatment.

Sociodemographic characteristics

We created a variable that combined survey information on race, ethnicity, and language. Women were asked first to indicate their race (white, black/African American, American Indian or Alaska Native, Asian or Pacific Islander, or some other race) and whether they were Hispanic/Latina (yes/no). In addition, women were asked whether they spoke Spanish. To determine language preference, we used the Short Acculturation Scale for Hispanics (SASH Manual), which has been demonstrated as an efficient, reliable, and valid measure to identify Latinas with low or higher acculturation.¹⁹ The 4 items indicate the preference for English or Spanish in different contexts (usually read/speak, think, use at home, use with friends) on a 5-point scale from "English only" to "Spanish only". We aggregated across the 5 items to calculate a mean preference score. Fifty-five percent of Latina patients ($n = 332$) scored ≥ 4 on the 5-point scale (strongly preferring Spanish across contexts). Thus, race/ethnicity was divided into 4 categories (white, African American, Latina-English preference [Latina-EP], and Latina-Spanish preference [Latina-SP]). Compared with Latinas who scored lower ($n = 271$), Latinas-SP (less acculturated) were much more likely to be foreign born (99.4% vs 35.2%). Because there were few African-American or white women who spoke Spanish, we included language preference as subcategories only for Latina women.

Additional factors that were included in the analyses were age at the time of breast cancer diagnosis, level of education (less than high school, high school diploma, and greater than high school diploma), marital status (currently married/domestic partner, divorced/widowed/separated, never married), num-

TABLE 1
Sample Characteristics Overall and by Race, Ethnicity, and Language (N=1137)

Characteristic	Percentage of Patients				
	Total (N=1137)	White (N=345)	African American (N=308)	Latina, English Preferred (N=268)	Latina, Spanish Preferred (N=303)
Sociodemographic factors					
Age, y					
<50	29	21	29	35	32
50-70	54	60	53	47	55
>70	17	19	18	18	13
Education					
<High school diploma	26	4	9	22	72
High school diploma	18	18	16	20	19
>High school	55	78	75	58	9
Marital status					
Currently married/partner	56	62	38	60	63
Divorced/widowed/separated	33	29	47	28	29
Never married	11	9	15	12	9
Clinical factors					
No. of comorbidities					
0	42	44	34	48	44
1	29	33	29	26	28
≥2	29	23	38	27	28
Breast cancer stage					
0	20	20	17	19	22
I	38	44	38	35	32
II	30	26	31	32	33
III	12	10	13	14	13
Treatment factors					
Surgery					
Lumpectomy	71	76	75	65	66
Mastectomy	29	24	25	35	34
Radiation therapy					
Yes	67	68	72	67	63
No	33	32	28	33	37
Chemotherapy					
Yes	50	40	51	55	57
No	50	60	49	45	43

*Chi-square test for association: age, $P = .003$; number of comorbidities, $P = .001$; breast cancer stage, $P = .186$; surgery, $P = .007$; radiation, $P = .177$; all others, $P < .001$. Percentages in the table are unweighted.

ber of comorbidities (0, 1, or ≥ 2), surgical procedure (lumpectomy or mastectomy), radiation therapy (yes/no), and chemotherapy (yes/no). Information on breast cancer stage was obtained from SEER data using criteria set forth by the American Joint Committee on Cancer (stages 0, I, II, and III). All women with stage IV cancer were deleted from this analysis.

Analysis Plan

All analyses were conducted using the SAS software program (version 9.1.3). Descriptive statistics were used to generate sample characteristics overall and by race/ethnicity. Bivariate associations between race/ethnicity and all sociodemographic, treatment, survivorship, and support-related factors were tested using the Wald chi-square test for association. Logis-

tic regression models were used to determine adjusted associations between race/ethnicity and treatment and survivorship-related factors. Because all hypotheses were determined a priori, we did not adjust for multiple comparisons. However, P values $< .001$ were considered statistically significant by the most conservative methods of controlling for multiple comparisons. Point estimates were adjusted for design effects by using a sample population weight that accounted for differential selection by race, ethnicity, and nonresponse.

RESULTS

The final analytic sample included 1137 women who had complete information available on all covariates of interest. Table 1 displays the sample characteris-

TABLE 2
Percentage of Women by Race and/or Ethnicity Who Received Treatment and Survivorship-related Information or Who Wanted More Information*

Issue	Received Information, % [†]					Wanted More Information, % [‡]				
	Overall	White	African American	Latina, English Preferred	Latina, Spanish Preferred	Overall	White	African American	Latina, English Preferred	Latina, Spanish Preferred
Treatment-related issues										
Surgical recovery	87	89	87	86	81	35	28	41	39	65
Radiation [§]	86	86	82	91	85	35	29	43	36	64
Chemotherapy	97	98	95	95	94	44	36	43	49	70
Survivorship-related issues										
Anxiety/depression	61	59	68	58	63	44	37	47	50	68
Relationships [¶]	39	34	59	51	44	41	35	48	45	65
Sexual function	32	28	41	43	37	33	29	34	39	50
Nutrition	52	49	63	57	54	53	49	53	59	70

*Percentages were weighted to account for differential selection by race, ethnicity, and nonresponse.

[†]Significant *P* values for those who received information were as follows: recovery, *P* = .047; nutrition, *P* = .004; relationship, *P* < .001; sexual function, *P* = .002.

[‡]All *P* values for women who wanted more information were < .001.

[§]Restricted to women who received radiation therapy.

^{||}Restricted to women who received chemotherapy.

[¶]Restricted to women who were married or living with someone.

tics overall and by race/ethnicity. The mean age was 56.9 years, and the racial/ethnic distribution was as follows: white, 27.7%; African American, 5.7%; Latina-EP, 21.4%; and Latina-SP, 25.2%. There were significant differences by race/ethnicity across all demographic characteristics, number of comorbidities, and treatment course variables, as presented in the Table (all *P* < .05 except breast cancer stage [*P* = .186] and receipt of radiation [*P* = .177]). African-American and Latina women were more likely to be aged <50 years at diagnosis. Latina-SP women were far more likely to have less than a high school education, and African-American women were less likely to be married. Latinas were more likely to receive mastectomy than other racial/ethnic groups. All minority groups were more likely to receive chemotherapy than whites.

Table 2 shows the percentage of women who reported receiving information and wanting more information across treatment-related and survivorship-related concerns. Overall, a higher percentage of women reported *receiving information* on treatment-related issues than on survivorship-related issues. At least 80% of women endorsed the receipt of information across treatment-related content areas; and, generally, there were no differences by race/ethnicity. However, there were greater differences reported on the receipt of information about survivorship issues, with a higher percentage of African Americans reporting the receipt of information in most content

areas compared with other ethnic/racial subgroups. With regard to *wanting more information*, significant racial/ethnic differences (all *P* < .001) were apparent across all treatment and survivorship-related concerns, with a higher percentage of Latina-SP women desiring more information on all issues. Finally, in a sensitivity analysis that compared our results with the results from women who still were receiving radiation and/or chemotherapy, the observed pattern of racial/ethnic differences remained the same (eg, a higher percentage of Latina-SP women desired more information on treatment-related issues).

Table 3 shows adjusted odds ratio (OR) for the desire to receive more treatment and survivorship information by sociodemographic factors, controlling for clinical and treatment-related factors. Race/ethnicity remained significant across all treatment and survivorship content areas, with Latina-SP women consistently wanting more information across all areas independent of other factors. For example, Latina women with low acculturation were much more likely to want more information about relationships than their white counterparts (OR, 4.84; 95% confidence interval [95% CI], 2.31–10.12). In addition to racial differences, older women (ages 50–70 years and aged >70 years) were less likely to want more information on sexual function than women aged <50 years (for women ages 50–70 years: OR, 0.53; 95% CI, 0.38–0.75; for women aged >70 years: OR, 0.10; 95% CI, 0.05–0.20). Older women also were less likely to

TABLE 3
Adjusted Odds of Wanting More Information by Sociodemographic Characteristics, Controlling for Clinical, and Treatment-related Factors*

Characteristic	OR (95% CI)						
	Surgical Recovery	Radiation†	Chemotherapy‡	Nutrition	Sexual Function	Relationships	Depression and/or Anxiety
Age, y							
<50	1.0	1.0	1.0	1.0	1.0	1.0	1.0
50-70	0.8 (0.57-1.13)	1.08 (0.70-1.66)	0.93 (0.60-1.43)	0.74 (0.53-1.03)	0.53 (0.38-0.75)	0.60 (0.39-0.93)	0.70 (0.50-0.97)
>70	1.1 (0.69-1.76)	1.09 (0.61-1.95)	1.33 (0.62-2.86)	0.44 (0.28-0.69)	0.10 (0.05-0.20)	0.11 (0.05-0.25)	0.42 (0.27-0.67)
Chi-square (P)	.131	.942	.572	.001	<.001	<.001	.001
Race and/or ethnicity							
White	1.0	1.0	1.0	1.0	1.0	1.0	1.0
African American	1.67 (1.13-2.47)	1.65 (1.02-2.65)	1.31 (0.78-2.20)	1.18 (0.80-1.74)	1.42 (0.92-2.18)	1.41 (0.73-2.69)	1.35 (0.92-1.97)
Latina, English preferred	1.53 (0.99-2.35)	1.20 (0.69-2.09)	1.52 (0.88-2.63)	1.54 (1.00-2.38)	1.52 (0.95-2.44)	1.36 (0.74-2.47)	1.65 (1.08-2.52)
Latina, Spanish preferred	4.54 (2.71-7.58)	3.07 (1.62-5.83)	2.83 (1.41-5.71)	3.02 (1.79-5.07)	3.76 (2.1-6.76)	4.84 (2.31-10.12)	4.07 (2.42-6.84)
Chi-square (P)	<.001	.003	.028	<.001	<.001	<.001	<.001
Education							
<High school	1.0	1.0	1.0	1.0	1.0	1.0	1.0
High school diploma	0.61 (0.36-1.00)	0.31 (0.16-0.59)	0.52 (0.26-1.05)	0.63 (0.38-1.04)	1.13 (0.61-2.06)	1.11 (0.52-2.34)	0.85 (0.51-1.41)
Some college/technical	0.94 (0.59-1.51)	0.6 (0.34-1.07)	0.57 (0.29-1.11)	1.34 (0.84-2.13)	2.02 (1.14-3.57)	1.95 (0.96-3.98)	1.27 (0.79-2.03)
Chi-square (P)	.044	<.001	.158	<.001	.005	.038	.075
Marital status							
Never married	1.0	1.0	1.0	1.0	1.0	N/A	1.0
Currently married	0.84 (0.55-1.28)	1.06 (0.59-1.88)	0.83 (0.49-1.40)	0.61 (0.39-0.95)	2.05 (1.28-3.26)		0.91 (0.60-1.40)
Divorced/widowed/separated	0.73 (0.46-1.15)	1.23 (0.67-2.27)	0.85 (0.47-1.53)	0.53 (0.33-0.84)	1.02 (0.61-1.70)		0.87 (0.55-1.37)
Chi-square (P)	.369	.673	.778	.026	<.001		.823

OR indicates odds ratio; 95% CI, 95% confidence interval; N/A, not applicable (the desire for more information on "relationships" was restricted to those who were married or with a partner).

*Adjusted for age, race, education, marital status, number of comorbidities, breast cancer stage, and treatment. Percentages were weighted to account for differential selection by race, ethnicity, and nonresponse.

†Restricted to women who received radiation therapy.

‡Restricted to women who received chemotherapy.

want more information about nutrition, relationships, and anxiety and depression. The impact of educational level was mixed. Women who had a high school diploma but no college, compared with women who had no high school diploma, were less likely to want additional information in 3 of the content areas (ie, surgical recovery, radiation side effects, and nutrition). However, women who had at least some college were more likely to want additional information on nutrition and sexual function than women who had less than a high school education. Married women and women who previously were married were more likely to want additional information on sexual function than women who were never married; however, they were less likely to want more information on nutrition.

Figure 1 shows the proportion of patients who reported challenges to understanding care and support information. About 48% of Latina-SP women reported some difficulty understanding the information presented, and 75% received help from others. Although 90% of women overall reported knowing who to ask regarding questions, Latina women as a

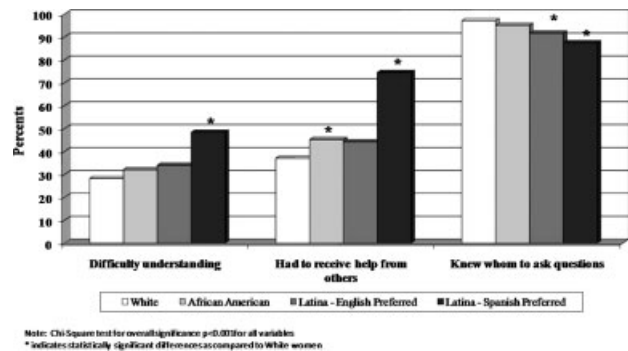


FIGURE 1. Understanding information on breast cancer treatment and receiving help from others by race/ethnicity (chi-square test for overall significance; $P < .001$ for all variables). Asterisks indicate statistically significant differences compared with white women.

whole were significantly less likely to know than white women.

Figure 2 shows the proportion of study participants who talked with other women and whether that happened through the medical care system or within their own social network. Latina-SP women

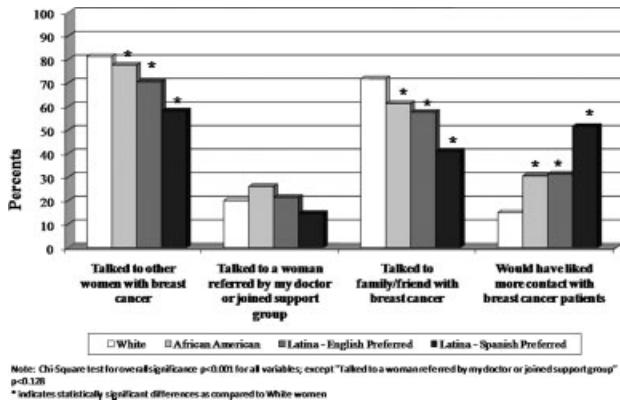


FIGURE 2. Opportunity to talk to other women with breast cancer by race/ethnicity (chi-square test for overall significance; $P < .001$ for all variables except 'Talked to a woman referred by my physician or joined support group', $P < .128$). Asterisks indicate statistically significant differences compared with white women.

were much less likely to talk with other women who had breast cancer than white women (58.2% vs 81.3%; $P < .001$). Latina-EP and African-American women were also less likely than white women to talk with other women who had breast cancer. Overall, 20% of women were referred by their medical care system to a support group and/or to an individual with breast cancer, and there was no significant variation by race/ethnicity. A much higher percentage of women reported talking to a family member or friend with breast cancer. African American and Latinas, however, were significantly less likely to report such an exchange compared with white women; Latina-SP were the least likely among the racial/ethnic groups. Finally, minority women were more likely than white women to desire more contact with breast cancer patients, particularly Latina-SP women (51.6% vs 14.9%; $P < .001$).

Figure 3 illustrates women's perceptions of the potential positive and negative consequences of talking with other women who had breast cancer (among those who had any contact). Three benefits of talking with other women were endorsed by >50% of the sample: 'helped me emotionally,' 'helped me know what to expect,' and 'helped me cope'. Each of the 3 potential negative consequences was endorsed by <10% of the women: 'made me scared,' 'made me wonder about my treatment,' and 'made me doubt my treatment decision.'

DISCUSSION

The results of this population-based study provide further insight into the information and support

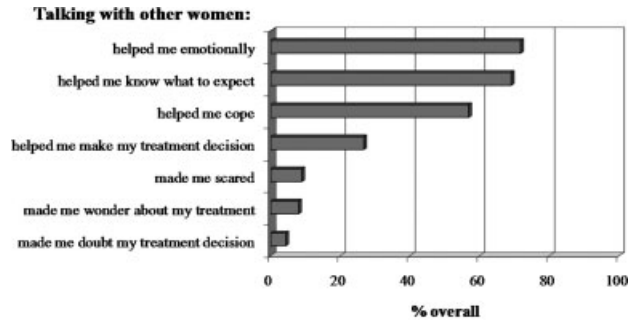


FIGURE 3. Experiences talking with other women with breast cancer.

needs of women with breast cancer and the extent to which they differ across racial/ethnic subgroups. Overall, most women with breast cancer, regardless of race/ethnicity, reported receiving substantial information on how to manage the side effects of treatment. Similar to other studies, substantially fewer women reported receiving information on common concerns related to survivorship.^{2,10} A considerable proportion of women wanted additional information on both treatment-related and survivorship-related information. The type of information desired varied by patient subgroup in logical ways. For example, younger women wanted more information on sexual functioning and relationships. These findings are consistent with other reports that women with breast cancer want more information in many content areas⁹ and that women have less exposure to survivorship-related concerns than to treatment-related concerns.^{2,10,21}

Particularly striking in our study are the racial/ethnic differences in perceptions of unmet need for information and peer support. Latinas with low acculturation appear to have the greatest unmet need for information support after controlling for other clinical and sociodemographic factors, including level of education, and the greatest unmet need for contact with other women who have breast cancer.

There are a number of explanations for the higher unmet need for information among Latinas with low acculturation. The first is that Latinas with low acculturation may not have access to information, particularly information about relationships, sexual health, and nutrition, or they may not be aware that such information is available. Medical practices that provide care for Latinas with low acculturation may not have trained staff available, including social workers and dieticians, whose role it is to help provide information on relationships and nutrition. In addition, if the information is available only in English, then it may present a barrier to Latinas with low acculturation. We observed that Latina-SP women reported needing the most help with

understanding information related to their breast cancer. This finding probably is related to the finding that only about 50% of Latina-SP women reported that their physician and/or someone at the medical clinic spoke Spanish. Previous studies have indicated that patients whose main spoken language is not English have more difficulty communicating with their physicians,²² including Latina breast cancer survivors.²³ Therefore, even if information had been provided, there may have been problems understanding or processing the information among Latina-SP women that led them to report desiring more information (or perhaps more well communicated information).

Another possible explanation for our findings on unmet information needs is that the information that was provided may not have been sensitive to cultural issues important to less acculturated Latinas. Others have reported that there is a need to provide culturally appropriate information related to health issues,^{1,15,24,25} and failure to account for culture and linguistic issues can result in less satisfaction with information provided. In ongoing work by our research team, we have observed that less acculturated Latinas report significantly higher levels of decision dissatisfaction and regret related to their treatment decision-making than other groups, suggesting that the desire for more information observed in the current study may be associated with decision outcomes.

Finally, Latinas with low acculturation may have greater need for information on particular topics than other women. That is, even when they are given adequate amounts of high-quality information, a greater level of need may lead to higher levels of unmet need. It is possible that concerns about recurrence, for example, are greater among Latinas and that more information about managing such concerns within the family may be helpful. Ongoing research addressing concerns about recurrence among women of different racial and ethnic groups may help to clarify the correlations between concerns about recurrence and the need for informational and peer support.

Some studies have suggested that ethnic minorities prefer to receive information through interpersonal contact rather than printed information.¹² Given the constraints on time in the physician's office, another avenue for women to gain information is to talk with other women who have breast cancer. The current study provided further evidence that most women who had an opportunity to talk with peers found it helpful, and very few found it counterproductive. Patient peer support was particularly helpful in the area of emotional well-being and coping. These

results are consistent with those reported by Ashing-Giwa et al.,²³ who observed that, although Latina survivors received most of their support from family and friends, talking with other women who had breast cancer provided a unique level of emotional support that was not available from other sources.

Despite the benefits of peer support, relatively few women reported that their healthcare provider arranged for such a contact. For example, only about 18% of Latina women either talked to other women who had breast cancer on the advice of their physician and/or joined a support group.

Limitations

The current study findings are limited by study design, which did not allow us to examine information needs over time. Because these were incident cases surveyed at the time of diagnosis and initial therapy (the mean time from diagnosis to survey completion was 9.2 months), we were not able to assess longer term needs. The results also were limited by the number of treatment and survivorship concerns assessed. There is a need to conduct multi-ethnic longitudinal evaluations of information and support needs among women after breast cancer and to assess the impact of changing information needs on health outcomes. A better understanding of longitudinal information needs will help in the design of more effective interventions. In addition, the generalizability of our findings regarding racial/ethnic differences is limited to the groups that were included in the sample (eg, we were unable to include Asian Americans). In addition, recall may have biased results. Women who were experiencing worse outcomes may recall either not having received sufficient information or wanting more information compared with their healthier counterparts. Finally, the origin of the Latina population in Los Angeles County predominantly is from Mexico and Central America. The U.S. Hispanic population is diverse, and it may not be appropriate to generalize our findings to Latinas from other cultural backgrounds.

Implications

Our current findings suggest that providing treatment and survivorship support for patients with breast cancer is challenging. Having written materials available in appropriate languages is one way to help address some of the challenges by providing information that can be taken home and reviewed in a more relaxed environment. Overcoming disparities in informational support also will require providing materials in a culturally relevant and sensitive manner.²⁶ When possible, using professional interpreters, new inter-

pre-ter technologies, or integrating community workers into practices also may be beneficial.^{27,28}

More challenging to clinicians and their staff is providing continuity of support beyond the immediate treatment period and into survivorship. Cancer survivorship support cannot be viewed in isolation from care and support needs for other health conditions. Cancer survivors need both continuity of care and integrated approaches to managing their cancer concerns along with other medical problems. The wide variation in follow-up of patients with cancer in the community underscores the need to design and evaluate collaborative care models between specialists and primary care.

A third strategy is to build more patient peer-support opportunities. This may be a missed clinical opportunity, especially for ethnic minority patients who appear to be particularly prone to unmet need in this area. More structured support-group referral programs could be integrated into provider offices and/or incorporated into the initial surgical consultation. For Latinas with low acculturation, ensuring that these referrals are to Spanish-speaking groups would be important. There is a variety of possible directions, from patient support groups, to trained patient support volunteers, to facilitating more informal arrangements. Indeed, some patients in our study reported that 'clinic friends' were an important source of information and support during treatment. More research will be required to evaluate interventions based on these strategies and to address the information and care support needs of patients with cancer into the survivorship period.

In conclusion, the findings from this population-based study have implications for clinical practice and future research. One of the strengths of this study was the use of a large, population-based sample of breast cancer survivors with adequate representation of Latina survivors (both low and high acculturated) and African-American survivors. Latina breast cancer patients, specifically those with low acculturation, reported more unmet information and care support needs than other racial/ethnic groups. Continued efforts to provide desired and culturally and linguistically appropriate information and support needs to women with breast cancer are necessary to achieve quality care.

REFERENCES

1. Arora N, Johnson P, Gustafson D, McTavish F, Hawkins RP, Pingree S. Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. *Patient Educ Couns.* 2002;47:37-46.
2. Griggs JJ, Sorbero MES, Mallinger JB, et al. Vitality, mental health, and satisfaction with information after breast cancer. *Patient Educ Couns.* 2007;66:58-66.
3. Mesters I, van den Borne B, DeBoer M, Pruyn J. Measuring information needs among cancer patients. *Patient Educ Couns.* 2001;43:255-264.
4. Arora N, Finney Rutten LJ, Gustafson DH, Moser R, Hawkins RP. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho-Oncology.* 2007;16:474-486.
5. Van Der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. *Eur J Cancer Care.* 1999;8:238-244.
6. Derdarian A. Information needs of recently diagnosed cancer patients: a theoretical framework. *Cancer Nurs.* 1987;10:107-115.
7. Reynolds PM, Sanson-Fisher RW, Poole AD, Harker J, Byrne MJ. Cancer and communication: information-giving in an oncology clinic. *Br Med J (Clin Res Ed).* 1998;282:1449-1451.
8. Raupach JCA, Hiller JE. Information and support for women following the primary treatment of breast cancer. *Health Expect.* 2002;5:289-301.
9. Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns.* 2005;57:250-261.
10. Gray RE, Fitch M, Greenberg M, Hampson A, Doherty M, Labrecque M. The information needs of well, longer-term survivors of breast cancer. *Patient Educ Couns.* 1998;33:245-255.
11. Salminen E., Vire J, Poussa T, Knif Sund S. Unmet needs in information flow between breast cancer patients, their spouses, and physicians. *Support Care Cancer.* 2004;12:663-668.
12. Maly RC, Leake B, Silliman RA. Health care disparities in older patients with breast carcinoma: informational support from physicians. *Cancer.* 2003;97:1517-1527.
13. Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns.* 2006;62:355-360.
14. Gray RE, Goel V, Fitch MI, Franssen E, Labrecque M. Supportive care provided by physicians and nurses to women with breast cancer: results from a population-based survey. *Support Cancer Care.* 2002;10:647-652.
15. Aziz NM, Rowland JH. Cancer survivorship research among ethnic minority and medically underserved groups. *Oncol Nurs Forum.* 2002;29:789-801.
16. Napoles-Springer A, Ortiz C, O'Brien H, Diaz-Mendez M, Perez-Stable EJ. Use of cancer support groups among Latina breast cancer survivors. *J Cancer Surviv.* 2007;1:193-204.
17. Owen JE, Goldstein MS, Lee JH, Breen N, Rowland JH. Use of health related and cancer-specific support groups among cancer survivors. *Cancer.* 2007;109:2580-2589.
18. Word DL, Perkins CR Jr. Building a Spanish Surname List for the 1990s—A New Approach to an Old Problem. Census Bureau, Technical Working Paper No. 13. Washington, DC: Population Division, U.S. Bureau of the Census; 1996.
19. Marin G, Sabogal F, Vanoos Marin B, Otero-Sabogal R, Perez-Stable EJ. Development of a short acculturation scale for Hispanics. *Hisp J Behav Sci.* 1987;9:183-205.

20. Anema MG, Brown BE. Increasing survey responses using the total design method. *J Contin Educ Nurs*. 1995;26:109-114.
21. Mallinger JB, Griggs JJ, Shields CG. Patient-centered care and breast cancer survivors' satisfaction with information. *Patient Educ Couns*. 2005;57:342-349.
22. Woloshin S, Schwartz LM, Katz SJ, Welch HG. Is language a barrier to the use of preventative services? *J Gen Intern Med*. 1997;12:472-477.
23. Ashing-Giwa KT, Padilla GV, Bohórquez DE. Understanding the breast cancer experience of Latina women. *J Psychosoc Oncol*. 2006;24:19-52.
24. Moore RJ, Burtow P. *Culture and Oncology: Impact of Context Effects*. New York, NY: Kluwer Academic Publishers; 2004.
25. Fatone AM, Moadel AB, Foley FW, Fleming M, Jandorf L. Urban voices: the quality-of-life experience among women of color with breast cancer. *Palliat Support Care*. 2007; 5:115-125.
26. Watts T, Merrell J, Murphy F, et al. Breast health information needs of women from minority ethnic groups. *J Adv Nurs*. 2004;47:526-535.
27. Corkery E, Palmer C, Foley ME, Schechter C, Frisher L, Roman SH. Effect of a bicultural community health worker on completion of diabetes education in a Hispanic population. *Diabetes Care*. 1997;20:254-257.
28. Palos G. Cultural heritage: cancer screening and early detection. *Semin Oncol Nurs*. 1994;10:104-113