Treatment Experiences of Latinas After Diagnosis of Breast Cancer

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BACKGROUND: The authors examined racial/ethnic differences in patient perspectives regarding their breast cancer treatment experiences. **METHODS:** A weighted random sample of women newly diagnosed with breast cancer between 2013 and 2015 in Los Angeles County and Georgia were sent surveys 2 months after undergoing surgery (5080 women; 70% response rate). The analytic sample was limited to patients residing in Los Angeles County (2397 women). **RESULTS:** The pattern of visits with different specialists before surgery was found to be similar across racial/ethnic groups. Low acculturated Latinas (Latinas-LA) were less likely to report high clinician communication quality for both surgeons and medical oncologists (<69% vs >72% for all other groups; *P*<.05). The percentage of patients who reported high satisfaction regarding how physicians worked together was similar across racial/ethnic groups. Latinas-LA were more likely to have a low autonomy decision style (48% vs 24%-50% for all other groups; *P*<.001) and were more likely to report receiving too much information versus other ethnic groups (20% vs <16% for other groups; *P*<.001). Patients who reported a low autonomy decision style to rate the amount of information they received for the surgery decision as "too much" (16% vs 9%; *P*<.001). **CONCLUSIONS:** There appears to be moderate disparity in breast cancer treatment decision making by Latinas-LA represents an important challenge to health care providers. Initiatives are needed to improve patient engagement in decision making and increase clinician awareness of these challenges in this patient population. *Cancer* 2017;123:3022-30. © *2017 American Cancer Society.*

KEYWORDS: breast cancer, Latina health, population-based observational studies, Surveillance, Epidemiology, and End Results (SEER) epidemiology studies, treatment communication and decision making, women's health.

INTRODUCTION

Efforts to improve cancer care delivery and outcomes have markedly changed the treatment experience for patients.¹⁻³ A key focus of these efforts has been reducing racial and ethnic disparities in the quality of treatment offered and improving the patient experience during and after treatment.⁴ Strategies that have been implemented include multidisciplinary approaches to treatment management, the use of care navigators to support patient decision making and care coordination, and a greater focus on patient support into survivorship. Taken together, these initiatives have the potential to reduce disparities in the treatment experience. However, the main focus has been on reducing disparities between African American and white patients. Indeed, recently published research has suggested that disparities in the initiation of treatment between these groups are small, perhaps reflecting the successes of these initiatives.⁵⁻¹¹ To the best of our knowledge, less is known regarding the treatment experiences of Latinas, a large and growing segment of the oncology patient population.

Although Latinas represent approximately 15% of patients with breast cancer in the United States,¹² understanding Latina breast cancer treatment disparities is complicated by the fact that the US Latina population comprises individuals from many countries and diverse levels of acculturation. Furthermore, a large sample is required to disentangle cultural

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factors from socioeconomic status (SES) factors because the majority of Latinas with low acculturation (Latinas-LA) also have low levels of education.

Latinas may be uniquely subject to disparate treatment due to language, cultural barriers, or fears of discrimination.¹³ For example, language limitations may make it more difficult to communicate with their providers and cultural values may discourage assertiveness and engagement, even when language skills are adequate. This may lead to differences in patient attitudes regarding treatment, the kind of treatment they receive, or their appraisal of the treatment experience. We examined racial/ethnic differences in the perspectives of patients with breast cancer regarding their treatment experiences, focusing on those of Latina patients of low and high acculturation, including practice factors and physician factors, attitudes regarding decision making, and appraisal of communication with clinicians.

MATERIALS AND METHODS

Study Population and Data Collection

The Individualized Cancer Care (iCanCare) Study is a population-based survey study of women with early-stage breast cancer and their providers. We identified and accrued a total of 7810 women aged 20 to 79 years with newly diagnosed, early-stage breast cancer (AJCC 7th Edition stages I-II) as reported to the Surveillance, Epidemiology, and End Results (SEER) registries of Georgia and Los Angeles County (LAC) from 2013 through 2015. Women were accrued on a monthly basis and Latinas were oversampled using a novel and valid approach based on patient surnames that were available at time of accrual.¹⁴ Patient surnames were compared with a list of names provided by the US Census Bureau, of whom \geq 50% indicated Hispanic ethnicity on the 2000 US census. All patients with surnames on the list were selected into the iCanCare accrued sample. Patients were ineligible if they had stage III or IV disease, Paget disease, or tumors measuring >5 cm; resided outside of the registry areas; or could not complete a questionnaire in English or Spanish (507 patients). Of the remaining 7303 eligible women who were mailed surveys, 5080 completed the survey, resulting in a 70% response rate (68%, 67%, 65%, and 73%, for Latina, African American, Asian, and white women, respectively). We limited the analytic sample for this study to patients residing in LAC because <3% of breast cancer cases in Georgia occur among Latinas. Women with missing data regarding race also were excluded from the analysis. The details regarding the analytic sample of 2397 women are shown in Supporting Information Figure 1.

Patients were identified shortly after diagnosis based on initial surgical pathology reports derived from a list of "definitive" surgical procedures (performed with the intent of removing the entire tumor and obtaining clear margins). Surveys were mailed approximately 2 months after surgery, with a median time from diagnosis to survey completion of 6.5 months (standard deviation, 3.2 months). Women were asked about their treatment experience, knowledge and attitudes, appraisal of clinician communication, and their decision-making process. To encourage response, we provided a \$20 cash incentive and used a modified Dillman approach to patient recruitment, including reminders to nonrespondents.¹⁵ All materials were sent in English and Spanish to those with Spanish surnames.¹⁴ A native Spanish-speaking project manager in LAC engaged all patients in follow-up, which included the offer of a full telephone interview if requested (and 19 completed) and recontact to complete missing data. Responses to the survey then were merged with clinical data by the SEER registries and a deidentified analytic data set was created. The study was approved by the University of Michigan Institutional Review Board and the state and Institutional Review Boards of the SEER registries.

Measures

The patient questionnaire content was guided by conceptual framework from a larger P01 Program Project supporting this analysis (grant P01CA163233), our prior work,¹⁶ research questions, and hypotheses. The items used in this analysis were taken from the P01 Program Project survey, in which we included established measures when available and developed new measures when necessary, drawing from the literature and our prior research.^{13,17-19} We used standard techniques to assess content validity, including review by survey design experts; cognitive pretesting with 50 patients with breast cancer; and pilot studies in selected clinic populations, including several with low SES patient populations. Nearly 100 instruments were reviewed and considered for inclusion in the patient survey. Survey measures for the program project questionnaire were compiled in a comprehensive catalogue describing constructs, pilot results, scoring details, and whether the measure had been previously developed in both English and Spanish. After questionnaire development, we posted any newly developed measures on our team Web site and the National Cancer Institute's Grid-Enabled Measures Database for

dissemination to other researchers. A Spanish version of the questionnaire was created using professional translation services and reviewed again by native Spanishspeaking project staff.

Practice and management factors

Patients were asked how they found out about the diagnosis of breast cancer (radiologist who performed the biopsy, primary care physician, surgeon or surgeon's nurse, or other), which types of specialists they consulted with before undergoing surgery, and what type of treatment they received (type of surgical management, radiotherapy, chemotherapy).

To assess perceived care coordination across clinicians, we asked respondents "During your breast cancer care, how satisfied were you with how your doctors worked together" (5-point Likert scale from "not at all" to "extremely satisfied").

Informal decision support

We asked patients to indicate how frequently family or friends engaged in treatment decision making by asking whether they: 1) attended physician appointments when decisions about treatment plans were made; and 2) took notes for the respondent during the physician's appointment (each on 5-point Likert scales from "never" to "very often").

Attitudes and beliefs regarding treatment decision making

We first assessed patient decision style with a single-item query: "When it came to getting treatment for breast cancer, I wanted my doctor to tell me what do" (5-point Likert scale from "none" to "all of the time"). Patients with a low autonomy decision style were defined as those patients who responded that they wanted their physician to tell them what to do "all of the time." We then assessed the degree to which patients believed that they deliberated or "thought through" their treatment, using a 4-item "decision deliberation" scale derived from measures of public deliberation adapted to apply to cancer treatmentrelated decisions.²⁰ Items assessed the extent to which a patient weighed the pros and cons of a decision, how much they thought through the issues important to the decision, how much they talked to others while they were making the decision, and how much they thought through and spent time thinking about the decision, and all had 5-point Likert scale response options (from "not at all" to "very much"). An overall deliberation score was created using the mean of the responses to the 4 items (range, 1-5), with higher scores representing more deliberation (alpha, .87). A score of \leq 3 indicated a less deliberative decision process. We used 3 items to assess a patient's perceptions regarding the adequacy of the amount of information they received concerning specific treatments using 1 item each for surgery, radiotherapy, and systemic chemotherapy¹⁹ (response categories were not enough, just right, too much, or not applicable if the physician did not offer the treatment).

Patient assessment of clinician communication quality

Clinician communication quality was examined using a modified version of the Health Care Climate Questionnaire scale,²¹ a scale specifically developed to assess patient perceptions of communication with clinicians. The scale assessed 4 domains by asking patients to report how often they thought their breast cancer clinicians (surgeon or oncologist was assessed separately): 1) "Understood how I saw things with respect to my breast cancer"; 2) "Listened to how I would like to handle my breast cancer treatment"; and 3) "Encouraged me to ask questions" (5point Likert scale from "not at all true" to "very true").¹⁷ Responses were summed and a cutoff of \geq 4.0 ("quite true" or "very true") was used to indicate high versus low physician communication quality.

Sociodemographic and other covariates

Racial/ethnicity categories were derived from patient report (white, black, Latina, Asian, and other). Latinas were divided further into those with low acculturation (Latinas-LA) and higher acculturation (Latinas-HA) based on the Short Acculturation Scale for Hispanics (SASH), which has been widely used to assess acculturation in Hispanics and previously was validated by our team in the Latina breast cancer population. The SASH includes 5 items related to the use of Spanish language in different contexts (reading, speaking, and thinking). Following methodologies developed and published in prior work, we summed and dichotomized the measure into low-score versus higher score groups using a median split.¹⁴ Low scores on the binary measure were an indication of low acculturation (Latinas-LA). We also assessed age, educational level, and health literacy using the singleitem validated measure.²² Additional patient-reported variables included country of origin, well-being at the time of survey completion (general self-reported health status ranging from poor to excellent), and number of medical comorbidities (0, 1, or ≥ 2) derived from a list pertinent to patients with cancer. We also included the

Characteristic	White n = 750	Black n = 327	Asian n = 418	Latina, Higher Acculturation n = 421	Latina, Low Acculturation n = 473	Total
Education						
<high school<="" td=""><td>117 (16%)</td><td>71 (22%)</td><td>62 (15%)</td><td>178 (43%)</td><td>366 (79%)</td><td>794 (34%)</td></high>	117 (16%)	71 (22%)	62 (15%)	178 (43%)	366 (79%)	794 (34%)
Some college or technical school	275 (37%)	146 (46%)	71 (17%)	145 (35%)	72 (16%)	709 (30%)
≥College graduate	350 (47%)	101 (32%)	280 (68%)	91 (22%)	25 (5%)	847 (36%)
Age, y						
≤50	91 (12%)	36 (11%)	123 (29%)	145 (34%)	163 (34%)	558 (23%)
51-65	360 (48%)	159 (49%)	199 (48%)	178 (42%)	195 (41%)	1091 (45%)
>65	298 (40%)	132 (40%)	96 (23%)	105 (25%)	117 (25%)	748 (31%)
No. of comorbidities						
0	552 (75%)	181 (57%)	286 (70%)	298 (71%)	302 (65%)	1619 (69%)
1	144 (19%)	101 (32%)	106 (26%)	92 (22%)	144 (31%)	587 (25%)
≥2	45 (6%)	37 (11%)	17 (4%)	28 (7%)	21 (4%)	148 (6%)
Health literacy						
High	507 (68%)	192 (60%)	185 (44%)	206 (49%)	93 (20%)	1183 (50%)
Low	234 (32%)	127 (40%)	232 (56%)	216 (51%)	381 (80%)	1190 (50%)
Health status						
Poor, fair	98 (13%)	78 (24%)	66 (16%)	88 (21%)	156 (33%)	485 (20%)
Good	245 (33%)	134 (41%)	170 (41%)	182 (44%)	208 (44%)	939 (40%)
Very good, excellent	399 (54%)	113 (35%)	179 (43%)	151 (36%)	106 (23%)	948 (40%)
Treatment						
BCS	530 (71%)	230 (71%)	207 (50%)	261 (63%)	287 (62%)	1515 (65%)
Unilateral mastectomy	111 (15%)	65 (20%)	140 (34%)	91 (22%)	129 (28%)	536 (23%)
Bilateral mastectomy	100 (14%)	26 (8%)	65 (16%)	64 (16%)	43 (9%)	298 (13%)

TABLE 1. Patient Characteristics by Racial/Ethnic Groups

Abbreviation: BCS, breast-conserving surgery.

All numbers are the column percentage by category and are unweighted. All differences by racial/ethnic differences were statistically significant (chi-square P <.001).

number of months between diagnosis and survey completion.²³

RESULTS

Statistical Analysis

We first described the distribution of population characteristics, practice and management factors, attitudes and beliefs about treatment decision making, informal decision support, and perceived care coordination by race/ethnicity. We then examined the percentage of patients who reported low autonomy decision style, low treatment deliberation, and low appraisal of the amount of information they received regarding the surgery decision by race/ ethnicity. These are presented as marginal probabilities based on multivariable logistic models that adjust for age, education, health status, comorbidities, health literacy, country of origin, months between diagnosis and survey completion, and treatments received. All models incorporated survey and nonresponse weights so that statistical inference was representative of the target population. Finally, we evaluated the relationship between patient reports of the adequacy of the amount of information received regarding the surgery decision and treatment decision style controlling for other factors.

Table 1 shows that the population was diverse with regard to education (approximately one-third of patients with an educational level of <high school), age (approximately 25% of patients aged \leq 50 years), and health literacy (approximately one-half of patients with low health literacy). Latinas-LA were found to be much more likely than other groups to have a lower educational level, to be of a younger age, to have low health literacy, and to have a poorer health status. Approximately 66% of the respondents reported they were born in Mexico, 21% in Central America, 8% in other Latin American countries, and 4% in the United States. The average number of years in the United States among first-generation Latinas was 30 (standard deviation, 12 years). The Asian patient population was very diverse (43% Filipino, 26% Chinese, 11% Korean, 11% Japanese, 4% Vietnamese, and 1% Asian Indian). Approximately 42% of patients found out about their diagnosis from a radiologist, 25% from their primary care physician, and 33% from their surgeon or surgeon's office, with no significant differences noted with regard to the source of diagnosis between Latinas-LA and other racial/ethnic groups. Rates of breast-conserving surgery varied from 50% among Asians to 71% among

	White	Black	Asian	Latina, Low Acculturation	Latina, Higher Acculturation	Overall	P-value ^a
Providers consulted before surgery							
Radiation oncologist	45%	47%	35%	41%	45%	43%	.005
Medical oncologist	47%	45%	48%	51%	58%	50%	.002
Plastic surgeon	26%	29%	30%	38%	26%	29%	.002
Primary care provider	53%	58%	55%	50%	52%	53%	.263
High clinician communication quality							
Surgeon	79%	76%	75%	77%	69%	76%	.001
Medical oncologist	74%	72%	76%	76%	67%	73%	.026
Satisfied with how physicians worked together	79%	81%	77%	77%	81%	79%	.001
Participation of family and friends in treatment decision making							
Attended physician appointments	68%	69%	73%	80%	77%	73%	.044
Took notes during appointment	48%	57%	53%	54%	61%	54%	.007

TABLE 2. Distribution of Practice and Decision Factors by Race/Ethnicity

^ap values test for difference between race/ethnic groups

non-Hispanic white women (P<.001), thereby reflecting the complexity of surgical treatment decision making.^{9,24}

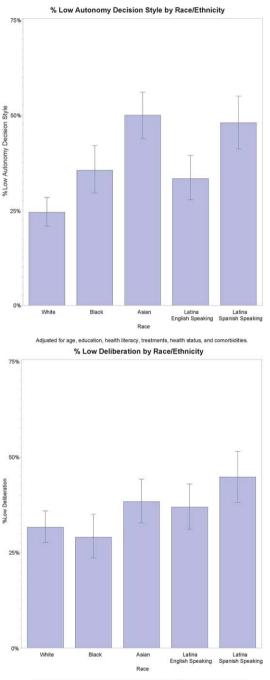
Table 2 shows the distribution of practice and decision appraisal factors by race/ethnicity. Patient reports of visits with different specialists before undergoing surgery were found to be very similar across racial/ethnic groups. Although there was similarly high appraisal regarding how physicians worked together during the breast cancer care continuum across racial/ethnic groups, when compared with other racial/ethnic subgroups, Latinas-LA were found to be less likely to report high clinician communication quality for both surgeons and medical oncologists (<69% vs >72% for all other groups; P<.05). It is important to note that patients reported a very high frequency of engagement of informal decision support. Nearly 75% of patients reported that a decision supporter often/very often attended visits and approximately onehalf reported that the support person took notes often/ very often. Latinas-LA had particularly high engagement of a decision support person: for example, 61% of Latinas-LA had a note taker often/very often compared with 48% to 57% for other ethnic groups (P = .007).

Figure 1 Top and Bottom show the marginal percentages of patients who reported a low autonomy decision style and low treatment deliberation by race/ ethnicity, respectively, from a multivariable logistic regression analysis controlling for age, education, health status, comorbidities, health literacy, country of origin, months between diagnosis and survey completion, and treatments received. The rates of both low autonomy decision style and low treatment deliberation varied significantly by race (P<.001 and P = .008, respectively). Overall, 34% of patients reported a low autonomy decision style. Latinas-LA were more likely to have a low autonomy decision style (48% vs 24%, 36%, 50%, and 33% for white women, African American women, Asian women, and Latinas-HA, respectively; P<.001). Approximately one-third of respondents (35%) reported low deliberation (45% vs 32%, 29%, 38%, and 37% for white women, African American women, Asian women, and Latinas-HA, respectively; P = .006).

Figure 2 shows marginal distribution of patient appraisal of the amount of information received regarding the surgery decision by race and ethnicity from a multivariable logistic regression analysis adjusting for the factors shown above. Latinas-LA were more likely to report receiving too much information (vs just right or too little) compared with other racial/ethnic groups (20% vs 7%, 10%, 16%, and 12% for white women, African American women, Asian women, and Latinas-HA, respectively; P<.001). Patients who reported a low autonomy decision style were more likely to rate the amount of information received for the surgery decision as too much (16% vs 8%; P<.001).

DISCUSSION

The findings in this large, diverse, and contemporary sample of patients recently diagnosed with breast cancer reinforce the special challenges Latinas-LA face when engaging health care providers after a diagnosis of cancer. Latinas-LA were found to have much lower levels of education and health literacy. Combined with low English fluency, these factors represent formidable barriers to high-quality communication and treatment decision making after a diagnosis of breast cancer. Nevertheless, we observed a remarkable lack of disparity in several important communication and treatment factors. We observed no substantial racial/ethnic gradients in multidisciplinary provider decision management or patient report of how



Adjusted for age, education, health literacy, treatments, health status, and comorbidities

Figure 1. (*Top*) Percentage of patients who reported a low autonomy decision style by race/ethnicity. (*Bottom*) Percentage of patients who reported low treatment decision deliberation by race/ethnicity. Presented rates are marginal probabilities derived from a multivariable logistic model controlling for age, education, health literacy, health status, and comorbidities. Vertical bars indicate 95% confidence intervals.

well physicians worked together. Furthermore, Latinas reported similarly high rates of engagement of informal decision support from family members or friends, such as attending a physician's appointment or taking notes during the appointment. Finally, rates of different treatments were found to be similar across the racial/ethnic groups. Taken together, this is strong evidence of the high quality of treatment communication and decision making reported by Latinas-LA, as well as by patients from other racial/ethnic groups.

However, we did observe some key significant differences with regard to patient care and patient experiences reported by Latinas compared with other patient groups. First, Latinas appear to approach treatment decision making differently from other cultural groups; we found that Latinas were more likely to report low autonomy decision styles (and thus are more likely to defer to clinicians) and to report limited deliberation regarding treatment types. It is interesting to note that Latinas-LA also were much more likely to report that they received too much information related to tests and treatments versus too little or just the right amount of information. This raises the possibility that a deferential decision style may lead to feeling overwhelmed by the complexity of treatment decision making for cancer. Indeed, the fact that Latinas-LA reported a lower appraisal of surgeon and medical oncologist quality of communication suggests they do not believe their providers are responding completely to their individual needs. This suggest a potential lack of cultural competency approaches to communication on the part of clinicians,²⁵ but also could be exacerbated by the lack of specific interpreter services in some settings. We also noted that Asians reported similar experiences with regard to low autonomy decision style and potential information overload. This reinforces that other ethnic groups may be vulnerable because of cultural or language barriers.

The prior literature focused on Latina experiences after a diagnosis of breast cancer is surprisingly sparse and variably executed, and to the best of our knowledge few studies to date have been population based^{13,16,26,27} and these studies are dated. Other studies have been limited by low response rates, small samples, or inadequate granular measures of communication and decision making.²⁸⁻³¹ Furthermore, these studies have tended to overreach with regard to conclusions regarding the presence of disparities based on very small differences between SES subgroups in a limited number of clinical settings. Nevertheless overall, the results of the current study identifying areas for improving the engagement of Latina patients in treatment decision making and patient-clinician communication are consistent with prior work that calls for more culturally tailored and patient-centered communication around cancer treatment.^{16,25,32}

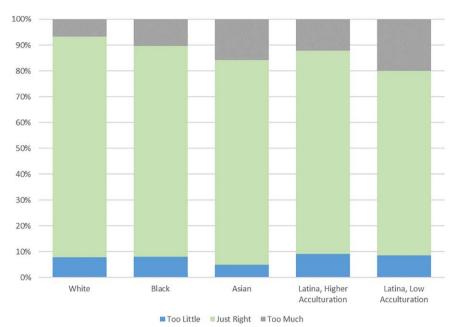


Figure 2. Patient report of the amount of information received regarding surgery treatment decisions by race/ethnicity. Presented rates are marginal probabilities derived from a multivariable logistic model controlling for age, education, health literacy, treatments, health status, and comorbidities. Values were weighted to reflect sampling and response rates.

Aspects of the current study merit comment. We oversampled Latinas using an innovative approach previously validated by our team¹⁴ and achieved a very high response rate that was nearly comparable among Latinas compared with other subgroups. We used established granular measures to assess patient perspectives regarding the treatment context and communication and decision making. We used sample weights to account for the sampling design and multiple imputation and sample weighting to address missing values and differential nonresponse. However, there are some limitations. Results are generalizable to one large metropolitan area of the United States containing >10 million individuals. As reflected in the results of the current study, Latinas in LAC predominantly are from Mexico and Central America. Thus, the results cannot necessarily be extended to Latinas from other areas of the world. We cannot exclude the possibility of response bias due to different interpretations of questions across cultural groups. We may have underrepresented patients with very low literacy levels because the dominant mode of inquiry was a written survey. We did not query patients about translation services or language fluency of the providers, although these factors are well-known barriers to care.³³⁻³⁵ Finally, the results of the current study regarding Asian patients are limited because of the highly diverse array of ethnic minorities within this group (over a different Asian populations in LAC) and dozen

translation of the questionnaire for each group was beyond the scope of the study. Furthermore, our measure of low acculturation, the SASH, to our knowledge has not been adopted or validated in other ethnic groups.

Implications for Patient Care

Taken together, the results of the current study suggest some positive news with regard to the lack of disparities in some key aspects of breast cancer treatment, including source of diagnosis, perceived coordination of services, and type of treatment. Despite these similar patterns, these results highlight that clinicians may face challenges in engaging Latinas with low acculturation in optimal treatment decision-making processes. Breast cancer decision making is increasingly complex and many patients feel the burden of decision making after diagnosis. Providers are increasingly encouraged to achieve patientcentered communication and shared decision making with their patients, yet this may be particularly difficult if patients are reluctant to participate. Latinas-LA may be particularly vulnerable, given that they desire less engagement in decision making and more often are overwhelmed with the amount of information. Other groups, including Asian Americans with low acculturation and language barriers, also may be vulnerable to lower quality decisionmaking processes. For these types of patients, cancer clinicians have a special responsibility to provide support in

their navigation of decision making and deliberation regarding treatment choices. Strategies to increase engagement and address these issues in this patient population could include communication skills and cultural competence training for clinicians.²⁵ The fact that many patients receive news of their diagnosis from nononcology providers underscores the need for this training even among providers not directly connected to cancer care.

Another key opportunity is to better involve informal decision support persons in the decision-making process. Indeed, the majority of patients (including Latinas-LA) reported having someone in the examination room and Latinas were most likely to have someone taking notes. This may provide an opportunity for clinicians to engage support persons to ensure that patients are comfortable with the information provided and proactive to address deficits. Taken together, these initiatives could ensure that shared decision making is optimally achieved for this important and growing population of patients with cancer who may face cultural or linguistic barriers.

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CONFLICT OF INTEREST DISCLOSURES

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AUTHOR CONTRIBUTIONS

Steven J. Katz: Conceptualization, methodology, investigation, writing-original draft, writing-review and editing, visualization, project administration, and funding acquisition. **Lauren P. Wallner**: Conceptualization, methodology, investigation, writing-original draft, and writing-review and editing. **Paul H. Abrahamse**:

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