

Treatment Experiences of Latinas After Diagnosis Of Breast Cancer

Running title: Latinas' breast cancer treatment experiences

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Precis: There is little disparity in breast cancer treatment communication and decision making experiences reported by Latinas with low acculturation vs other groups. However, the approach taken by Latina patients with low acculturation with regard to treatment decision making represents an important challenge to health care providers.

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Abstract

Objectives: We examined race/ethnic differences in patient perspectives about their breast cancer treatment experiences.

Methods: A weighted random sample of women newly diagnosed with breast cancer in 2013-15 in Los Angeles County and Georgia were sent surveys 2 months after surgery (N=5,080, 70% response rate). The analytic sample was limited to patients in Los Angeles County (N=2,397).

Results: The pattern of visits with different specialists before surgery was similar across race/ethnic groups. Low acculturated Latinas (Latinas-LA) were less likely to report high clinician communication quality for both surgeons and medical oncologists (under 69% vs over 72% for all other groups, $p < .05$). The proportion of patients who reported high satisfaction about how doctors worked together was similar across race/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 getting too much information vs other ethnic groups (20% vs <16% for other groups, $p < .001$). Patients who reported a low autonomy decision style were more likely to rate amount of information received for the surgery decision as “too much” (16% vs 9%, $p < .001$).

Conclusions: There is moderate disparity in breast cancer treatment communication and decision making experiences reported by Latinas with low acculturation vs other groups. The approach to treatment decision making by Latinas with low acculturation 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.

Key words: breast cancer, Latina health, treatment communication and decision making, women's health, population-based observational studies, SEER epidemiology studies.

INTRODUCTION

Efforts to improve cancer care delivery and outcomes have markedly changed the treatment experiences 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, 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 for reducing disparities in the treatment experience. However, the main focus has been on reducing disparities between African American and whites. Indeed, recent published research suggests disparities in initiation of treatment between these groups are small, perhaps reflecting the successes of these initiatives.⁵⁻¹¹ Less is known about the treatment experiences of Latinas, a large and growing segment of the oncology patient population.

Although Latinas represent about 15% of patients with breast cancer in the US,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 factors from SES factors because most low acculturated Latinas 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 about treatment, the kind of treatment they get or their appraisal of the treatment experiences. We examined race/ethnic differences in breast cancer patient's perspectives about their treatment experiences, focusing on those of Latina patients of low and high

acculturation, including practice factors and physician factors, attitudes about decision making, and appraisal of communication with clinicians.

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 7,810 women aged 20-79 with newly diagnosed, early-stage breast cancer (stages I-II) as reported to the SEER registries of Georgia and Los Angeles County (LAC) in 2013-2015. Women were accrued on a monthly basis and Latinas were oversampled using a novel and valid approach based on patient surnames which were available at time of accrual.¹⁴ Patient surnames were compared to a list of names provided by the US Census Bureau of whom 50% or more 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's disease, tumors larger than 5cm, resided outside the registry areas, or could not complete a questionnaire in English or Spanish (N= 507). Of the remaining 7,303 eligible women who were mailed surveys, 5,080 completed the survey, resulting in a 70% response (68%, 67%, 65%, 73% for Latinas, AA, Asians, and Whites, respectively). We limited the analytic sample for this study to patients residing in Los Angeles County (LAC) because less than 3% of breast cancer cases in Georgia are Latina. Women with missing race data were also excluded from the analysis. The details of the analytic sample of 2,397 women are displayed in Figure 1 Supplemental.

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 median time from diagnosis to survey completion of 6.5 months (SD 3.2). Women

were asked about their treatment experiences, 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 non-respondents.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 phone interview if requested (and 19 completed) and re-contact to complete missing data. Responses to the survey were then merged with clinical data by the SEER registries and a de-identified analytic dataset was created. The study was approved by the University of Michigan Institutional Review Board and the state and institutional IRBs of the SEER registries.

Measures

The patient questionnaire content was guided by conceptual framework from a larger P01 Program Project supporting this analysis (P01CA163233, The Challenges of Individualizing Treatment for Patients with Breast Cancer, PI: Katz SJ), our prior work,¹⁹ research questions and hypotheses. The items used in this analysis were taken from the P01 Program Project survey, where we included established measures when available and developed new measures, when necessary, drawing from the literature and our prior research.^{13,16-18} We used standard techniques to assess content validity, including review by survey design experts, cognitive pre-testing with 50 breast cancer patients, 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. Following questionnaire development, we posted any newly developed measures on our team website and NCI'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 Spanish native speaking project staff.

Practice and management factors: Patients were asked how they found out about the diagnosis of breast cancer (radiologist who did the biopsy, primary care doctor, surgeon or surgeon's nurse, or other) and which types of specialists they consulted with before surgery, and what type of treatment they received (type of surgical management, radiation, 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 pts 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 doctor appointments where decisions about treatment plans were made, and 2) took notes for the respondent during the doctor's appointment (each on 5-pt Likert scales from never to very often).

Attitudes and beliefs about 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 pt Likert scale from none to all of the time). Low autonomy decision style was defined as those who responded they wanted their doctor to tell them what to do "all of the time". We then assessed the degree to which patients felt that they deliberated, or "thought through" regarding their treatment, using a 4-item "decision deliberation" scale derived from measures of public deliberation adapted to apply to cancer treatment-related 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-pt 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 four

items (range 1-5), with higher scores representing more deliberation (alpha .87). A score of 3 or less indicated a less deliberative decision process. We used 3 items to assess patient's perceptions about the adequacy of the amount of information they received about specific treatments using 1 item each for surgery, radiation, and systemic chemotherapy²¹ (response categories were not enough, just right, too much, or not applicable if doctor did not offer the treatment).

Patient assessment of clinician communication quality: This was examined using a modified version of the Health Care Climate Questionnaire Scale,²² 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 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" (5 pt Likert scale from not at all true to very true).²³ Responses were summed and a cutoff of 4.0 or greater (quite true or very true) was used to indicate high vs. low physician communication quality.

Sociodemographic and other covariates: Race/ethnicity categories were derived from patient report (White, Black, Latina, Asian, other). Latinas were further divided into low and higher acculturation (Latinas-LA, Latinas-HA) based on the Short Acculturation Scale for Hispanics (SASH) which has been widely used to assess acculturation in Hispanics, and previously been validated by our team in the Latina breast cancer population. The SASH includes 5 items related to use of Spanish language in different contexts (read, speak, think). Following methodologies developed and published in prior work, we summed and dichotomized the measure into low versus higher score groups using a median split.¹⁴ Low scores on the binary measure was indication of low acculturation (Latina-LA). We also assessed age, education

level, and health literacy using the single item validated measure.²⁴ Additional patient reported variables included country of origin, well-being at the time of survey completion (general self-reported health status from poor to excellent), and medical comorbidities (0, 1, 2 or more) derived from a list pertinent to cancer patients. We also included number of months between diagnosis and survey completion.²⁵

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 proportion 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 which 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 non-response weights so that statistical inference is representative of the target population. Finally, we evaluated the relationship between patient reports of the adequacy of the amount of information received about the surgery decision and treatment decision style controlling for other factors.

RESULTS

Table 1 shows that the population was diverse with regard to education (one third high school or less), age (one quarter age 50 or less), and health literacy (one half with low health literacy). Latinas-LA were much more likely than other groups to be lower educated, younger age, have low health literacy, and poorer health status. Two thirds (66%) 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 US among first generation Latinas was 30 (SD

12). The Asian patient population was very diverse (43% Filipino, 26% Chinese, 11% Korean, 11% Japanese, 4% Vietnamese, 1% Asian Indian). Forty-two percent of patients found out about their diagnosis from a radiologist, 25% from their primary care doctor, and 33% from their surgeon or surgeon's office, with no significant differences in source of diagnosis between Latinas-LA and other race/ethnic groups. Rates of breast conserving surgery option varied from 50% among Asians to 71% among White-non Latinas ($p < .001$) reflecting the complexity of surgical treatment decision-making.^{9,26}

Table 2 shows the distribution of practice and decision appraisal factors by race/ethnicity. Patient report of visits with different specialists prior to surgery were very similar across race/ethnic groups. Although, there was similarly high appraisal regarding how doctors worked together during the breast cancer care across race/ethnic groups, when compared to other race/ethnic subgroups, Latinas-LA were less likely to report high clinician communication quality for both surgeons and medical oncologists (under 69% vs over 72% for all other groups, $p < .05$). Importantly, patients reported very high frequency of engagement of informal decision support. Nearly three quarters reported that a decision supporter often/very often attended visits and half reported that 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 to 48%-57% for other ethnic groups ($p = .007$).

Figure 1a and 1b show the marginal percentages of patients who reported low autonomy decision style and low treatment deliberation by race/ethnicity, from a multivariable logistic regression which controls 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 styles and low treatment deliberation varied significantly by race ($p < .001$, $p = .008$). Overall, 34% 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 whites, AA, Asians, and Latinas-HA, $p < .001$). About one third (35%) reported low deliberation (45% vs 32%, 29%, 38% and 37% for whites, AA, Asians, and Latinas-HA, $p = .006$)

Figure 2 shows marginal distribution of patient appraisal of amount of information received regarding the surgery decision by race and ethnicity, from a multivariable logistic regression adjusting for the factors above. Latinas-LA were more likely to report getting too much information (vs just right or too little) than other racial/ethnic groups (20% vs 7%, 10%, 16% and 12% for whites, AA, Asians, and Latinas-HA, respectively $p < .001$). Patients who reported a low autonomy decision style were more likely to rate amount of information received for the surgery decision as too much (16% vs 8%, $p < .001$).

DISCUSSION

Our findings in this large, diverse and contemporary sample of patients recently diagnosed with breast cancer reinforce the special challenges Latinas with low acculturation (Latinas-LA) face when engaging health care providers after a diagnosis of cancer. Latinas-LA had 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 diagnosis of breast cancer. Yet, we observed a remarkable lack of disparity in a number of important communication and treatment factors. We observed no substantial race/ethnic gradients in multi-disciplinary provider decision management or patient report of how well doctors worked together. Furthermore, Latinas reported similarly high rates of engagement of informal decision support from family members or friends, such as attending a doctor's appointment or taking notes during the appointment. Finally, rates of different treatments were similar across the race/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 race/ethnic groups.

However, we did observe some key significant differences in patient care and patient experiences reported by Latinas compared with other patient groups. First, Latinas appear to approach treatment decision making differently than other cultural groups; we found that Latinas were more likely to report low autonomy decision styles—thus more likely to defer to clinicians—and to reported limited deliberation about treatment types. Interestingly, Latinas-LA were also much more likely to report that they had *too much* information related to tests and treatments vs. 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 lower appraisal of surgeon and medical oncologists quality of communication suggests they do not feel their providers are responding completely to their individual needs. This suggest potential lack of cultural competency approaches to communication on the part of clinicians,²⁷ but could also be exacerbated by lack of specific interpreter services in some settings. We also note 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 experience after diagnosis of breast cancer is surprisingly sparse and variably executed. Few studies have been population-based^{13,19,28,29} 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.³⁰⁻³³ Furthermore, these studies have tended to overreach with regard to conclusions about the presence of disparities based on very small differences between SES subgroups in limited number of clinical settings. Yet overall, the results of this 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.^{19,27,34}

Aspects of the study merit comment. We oversampled Latinas using an innovative approach previously validated by our team.¹⁴ and achieved a very high response rate nearly comparable among Latinas compared with other subgroups. We used established granular measures to assess patient's perspectives about 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 non-response. However, there are some limitations. Results are generalizable to one large metropolitan area of the United States containing over 10 million people. As reflected in our results, Latinas in Los Angeles County are predominantly from Mexico and Central America. Thus, results cannot be necessarily 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 under-represented 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, though these factors are well-known barriers to care.³⁵⁻³⁷ Finally, our results regarding Asian patients are limited because of the highly diverse array of ethnic minorities within this group (over a dozen different Asian populations in LA county) and translation of the questionnaire for each group was beyond the scope of the study. Furthermore, our measure of low acculturation, the Short Acculturation Scale for Hispanics, has not been adopted or validated in other ethnic groups.

Implications for patient care

Taken together, our results 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, our results highlight clinicians may face challenges to engaging the Latina-Low acculturation population 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 patient centered communication and shared decision making with their patients, yet this may be particularly difficult if patients are reluctant to participate. Latinas with low acculturation may be particularly vulnerable, given they desire less engagement in decision making and are more often overwhelmed with the amount of information. Other groups, including Asian Americans with low acculturation and language barriers, may also be vulnerable to lower quality decision making processes. For these types of patients, cancer clinicians have a special responsibility to support them in navigation of decision making and deliberation about treatment choices. Strategies to increase engagement and address these issues in this patient population could include communication skills and cultural competence training for clinicians.²⁷ The fact that many patients receive news of their diagnosis from non-oncology providers, underscores the need for this training even in providers not directly connected to the cancer care.

Another key opportunity is to better involve informal decision support people in the decision making process. Indeed, most patients (including Latinas with low acculturation) reported having someone in the exam room and Latinas were most likely to have someone taking notes. This may provide an opportunity for clinicians to engage support people 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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FIGURE LEGENDS

Figure 1: 1a) Percentage of patients who reported a low autonomy decision style by race/ethnicity; **1b)** 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 are 95% confidence intervals.

Figure 2: Patient report of the amount of information they 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. Weighted to reflect sampling and response rates.

Figure 1 Supplemental: Patient flow into the study. This figure depicts the flow of patients into the study from those initially identified to the final analytic sample.

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533 Table 1: Patient Characteristics by Race/Ethnic Groups

	White (n=750)	Black (n=327)	Asian (n=418)	Latina, Higher Acculturation (n=421)	Latina, Low Acculturation (n=473)	Total
Education						
High School or Less	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 or More	350 (47%)	101 (32%)	280 (68%)	91 (22%)	25 (5%)	847 (36%)
Age						
50 or Less	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%)
Over 65	298 (40%)	132 (40%)	96 (23%)	105 (25%)	117 (25%)	748 (31%)
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 Health Literacy	507 (68%)	192 (60%)	185 (44%)	206 (49%)	93 (20%)	1183 (50%)
Low Health Literacy	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%)

534 All numbers are column % by category and are unweighted. All differences are significant (chi-square
535 $p < .001$)

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542 **Table 2: Distribution of Practice and Decision Factors by Race/Ethnicity**

	White	Black	Asian	Latina, Low Acculturation	Latina, Higher Acculturation	Overall
Providers Consulted before Surgery						
Radiation Oncologist (p=.005)	45%	47%	35%	41%	45%	43%
Medical Oncologist (p=.002)	47%	45%	48%	51%	58%	50%
Plastic Surgeon (p=.002)	26%	29%	30%	38%	26%	29%
Primary Care Provider (p=.263)	53%	58%	55%	50%	52%	53%
High Clinician Communication Quality						
Surgeon (p=.001)	79%	76%	75%	77%	69%	76%
Medical Oncologist (p=.026)	74%	72%	76%	76%	67%	73%
High Satisfaction with How Doctors Worked Together (p=.001)						
	79%	81%	77%	77%	81%	79%
Participation of family and friends in treatment decisions						
Attended Doctor Appointments (p= .044)	68%	69%	73%	80%	77%	73%
Took Notes during Appointment (p=.007)	48%	57%	53%	54%	61%	54%

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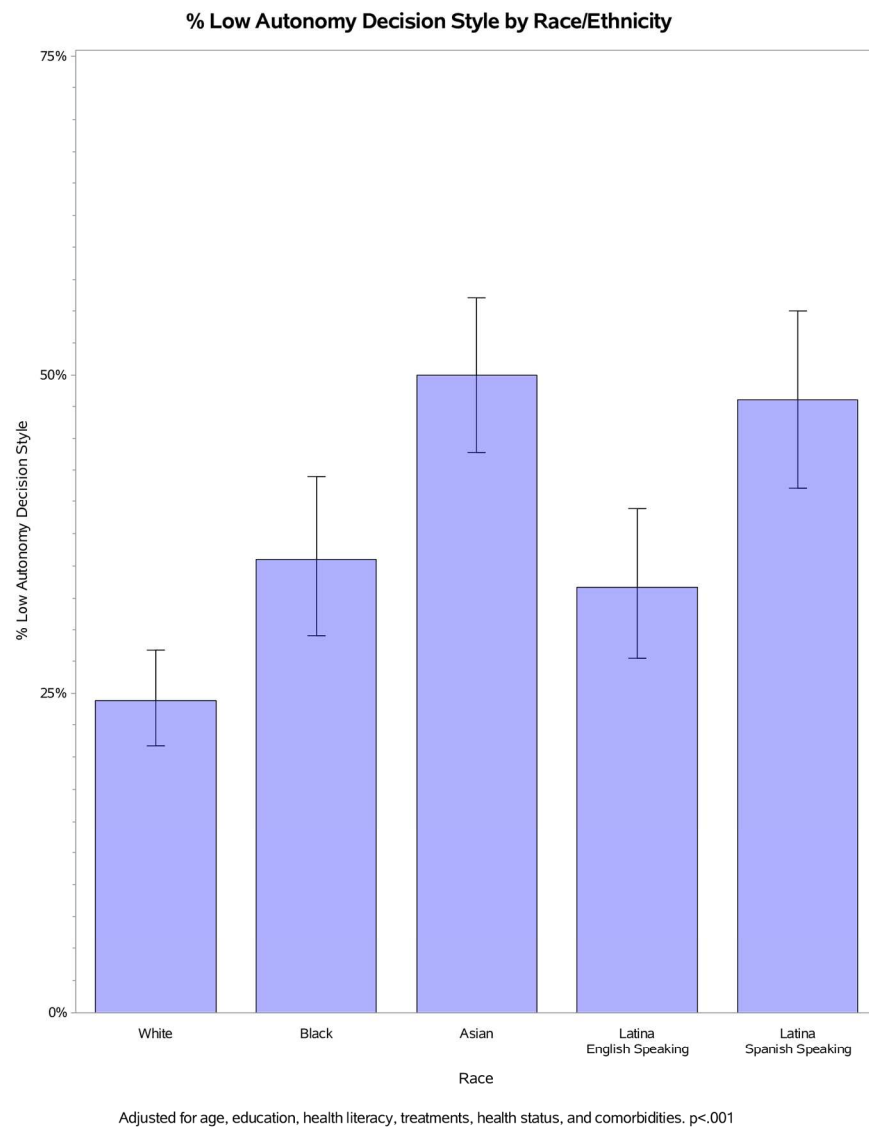


Figure 1a: Percentage of patients who reported a low autonomy decision style by race/ethnicity. Presented rates are marginal probabilities derived from a multivariable logistic model controlling for age, education, health literacy, health status, and comorbidities. Vertical bars are 95% confidence intervals.

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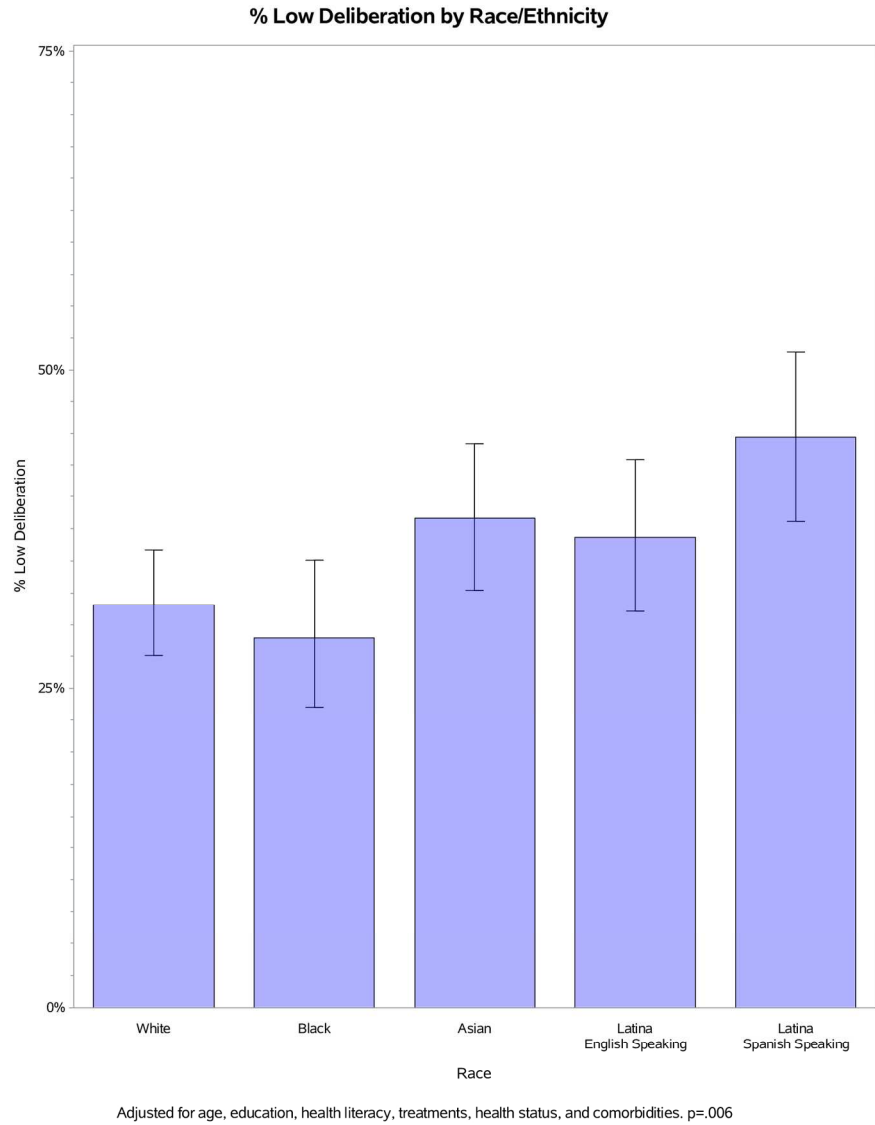


Figure 1b: Percentage of patients who reported low treatment decision deliberation by race/ethnicity. Presented rates are marginal probabilities derived from a multivariable logistic model controlling for age, education, health literacy, health status, and comorbidities. Vertical bars are 95% confidence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

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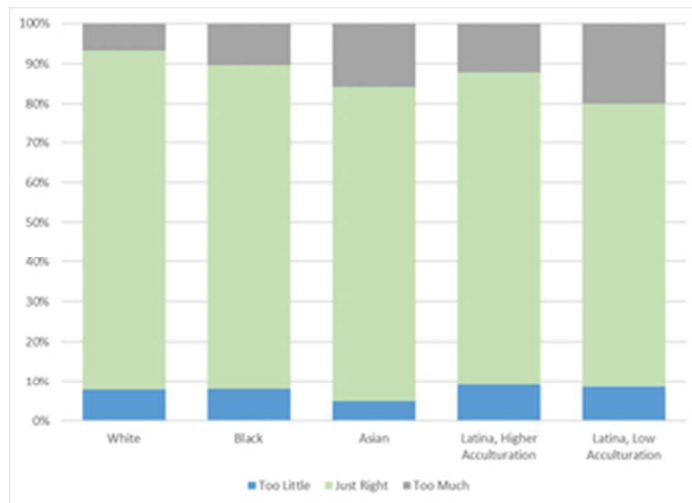
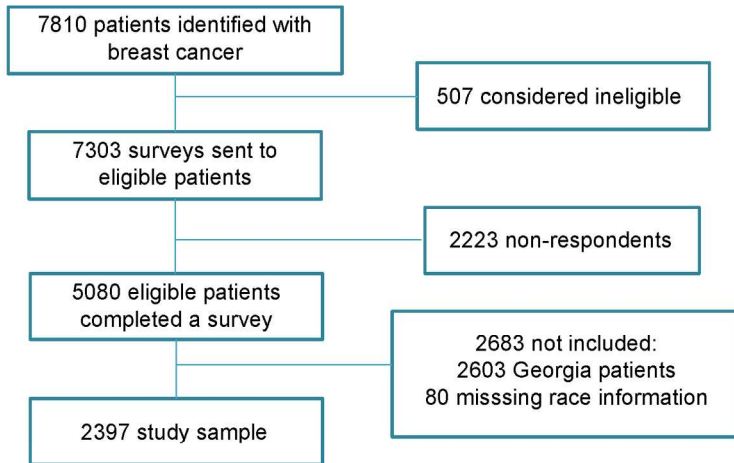


Figure 2: Patient report of the amount of information they received regarding surgery treatment decisions by race/ethnicity. Presented rates are marginal probabilities derived from a multivariable logistic model controlling for age, education, health literacy, treatments, health status, and comorbidities.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

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