

Latina patient perspectives about informed treatment decision making for breast cancer

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ABSTRACT

Objective: To evaluate Latina breast cancer patient perspectives regarding informed decision making related to surgical treatment decision making for breast cancer.

Methods: 2030 women with non-metastatic breast cancer diagnosed from 8/05 to 5/06 and reported to the Los Angeles metropolitan SEER registries were mailed a survey shortly after surgical treatment. Latina and African-American women were over-sampled. We conducted regression of four decision outcome to evaluate associations between race/ethnicity, demographic and clinical factors, and mechanistic variables (i.e., health literacy) and decision outcomes.

Results: Our analytic sample was 877 women: 24.5% Latina-Spanish speaking (Latina-SP), 20.5% Latina-English speaking, 24% African-American and 26.6% Caucasian. Approximately 28% of women in each ethnic group reported a surgeon-based, 36% a shared, and 36% a patient-based surgery decision. Spanish-preferent Latina women had the greatest odds of high decision dissatisfaction and regret controlling for other factors (OR 5.5, 95% CI: 2.9, 10.5 and OR 4.1, 95% CI: 2.2, 8.0, respectively). Low health literacy was independently associated with dissatisfaction and regret (OR 5.6, 95% CI: 2.9, 11.1 and OR 3.5, 95% CI 1.8, 7.1, respectively) and slightly attenuated associations between Latina-SP ethnicity and decision outcomes.

Conclusion: Despite similar clinical outcomes, patients report very different experiences with treatment decision making. Latina women, especially those who prefer Spanish, are vulnerable to poor breast cancer treatment decision outcomes.

Practice implications: Providers need to be aware of the role of ethnicity, acculturation and literacy in breast cancer treatment discussions.

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1. Introduction

There is a growing body of literature related to patterns of breast cancer treatment decision making. However, little of it has evaluated racial/ethnic differences in involvement and virtually none has included a large proportion of Latina patients [1,2]. Research has found that not all patients desire an active role in all

decisions [3–7]. Furthermore, a substantial proportion of patients report a mismatch between their actual versus preferred role in surgical treatment decisions, with patients reporting having both too little and too much involvement [6–10]. This mismatch is associated with lower patient satisfaction with both the decision making process and choice of treatment [6,7]. At the same time, research suggests that informed decision making for breast cancer treatment is lacking for African-American women and possibly other racial minorities [11,12]. These results imply that racial minorities may be at particular risk for making poor quality breast cancer treatment decisions. However, a major limitation of the current literature is the paucity of reports focusing on the treatment experience of Latina women with breast cancer.

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Latinas comprise a growing proportion of the general population and are increasingly represented among women diagnosed with breast cancer [13]. Although increasing informed decision making has been highlighted as a mechanism for improving patient centered care – especially for racial/ethnic minorities [14–16] – few published reports have addressed Latina perspectives regarding cancer decision involvement and outcomes. Some studies suggest that Latina breast cancer patients may experience barriers to informed treatment decision making related to literacy, language and acculturation [1,2,17,18]. However, the reports have been limited by small samples in selected clinical settings. Thus, more research is needed with larger samples of Latinas in comparison to other racial/ethnic groups in more generalizable settings [1].

To address the gap in the literature, this paper addresses two research objectives: (1) to examine the degree to which Latina women (Spanish and English preferent) with breast cancer participate in informed surgical breast cancer treatment decision making compared to other race/ethnic groups and (2) to evaluate factors associated with the desired amount of involvement and informed decision making for surgical breast cancer treatment across racial/ethnic groups. In addition, we assessed some potential mechanisms for racial/ethnic differences in decision outcomes.

2. Methods

2.1. Study population

Los Angeles County resident women aged 20–79 years diagnosed with primary ductal carcinoma in-situ (DCIS) or invasive breast cancer (Stage I, II or III) from August 2005 through May 2006 were eligible for sample selection for the study. We excluded patients with stage 4 breast cancer, those who died prior the deployment of the survey, and those who could not complete a questionnaire in English or Spanish.

2.2. Sampling

Patients were selected shortly after diagnosis on a monthly basis as they were reported to the Los Angeles Cancer Surveillance Program (LA-CSP), 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 over-sampled African-American (AA) women and Latinas to increase their representation in the dataset. To do so, the LA-CSP identified all women meeting the eligibility criteria of AA race based on the demographic information available from the SEER data. Because Latina status is not accurately collected by the treating hospital at the time of diagnosis, and therefore not reliably included in the SEER data, 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 [19]. We then selected an approximately 11% random sample of the remaining white (non-Spanish surnamed) patients meeting eligibility criteria. Asian women were excluded because these women were already being enrolled in other studies.

Over the study period, 1766 eligible patients were accrued including 796 Latinas, 459 African-Americans, 478 Caucasians, and 33 patients of other race/ethnicity. The accrued sample included approximately two thirds of the Latina and AA patients and 14% of White patients diagnosed with breast cancer in LA County during the study period. Sixty-eight patients were excluded because: (1) physician refused permission to contact (7), (2) the patient did not speak English or Spanish (8), (3) the patient was too ill or

incompetent to participate (30), and (4) the patient denied having cancer (23). Of the 1698 patients included in the final accrued sample, 179 (10.5%) could not be located or contacted and 296 (17.5%) did not participate in the survey. A final sample of 1224 (72.0%) completed the survey. Our power calculations were based on extensive modeling using a prior population-based dataset of breast cancer patients, and the numbers of available Latina and AA breast cancer patients in the LA SEER catchment area. Our approach to over-sampling by race/ethnicity resulted in one of the largest and most racially/ethnically diverse samples ($N = 1224$) with sufficient power to test the study hypotheses.

2.3. Data collection and management

Physicians were notified of our intent to contact patients. If the physician did not refuse, we applied a modified Dillman survey method to encourage response [20]. This method involves the mailing of an introductory letter, risk and benefit informed consent sheet, survey materials with return envelope, and \$ 10 cash gift. All patients who were likely to be Latina based on hospital or surname-based census information were sent bilingual materials that were translated into Spanish using a standard approach [21]. The correspondence between those identified with a Spanish surname and self-reporting Latina ethnicity was 98.2%. The Dillman method then involves telephone follow up to encourage response and post-card reminders for those without telephones, with a telephone survey option offered as a last report. Twenty-seven of the 1224 participants completed a telephone survey. Of these, 21 were Latinas, and 15 were conducted in Spanish. The survey procedures followed protocols established by the LA County SEER site. The study protocol was approved by the Institutional Review Boards of the University of Michigan and the University of Southern California.

Information from the survey was merged to SEER data for all patients in the final sample. An analysis of non-respondents vs. respondents showed no significant differences by age at diagnosis, or race/ethnicity. However, compared to respondents, non-respondents were less likely to have ever married (18.9% vs. 25.2%, $p = .005$), more likely to live in lower SES census tracts (48.6% vs. 40.2%, $p = .030$), more likely to have stage II or III disease (45.7% vs. 40.3% $p < .001$), and less likely to have received breast conserving surgery (BCS) (56.0% vs. 64.4%, $p < .001$).

For this analysis, we included women whose documented summary stage in SEER was DCIS, I, II or IIIa based on treatment guidelines of both the National Cancer Institute Physician Data Query (NCI-PDQ) database and the National Comprehensive Cancer Network (NCCN) that describe both mastectomy and BCS with radiation as viable options for these stages of cancer [22,23]. We excluded women with a self-reported clinical contraindication to BCS (about 20% of the sample).

2.4. Measures

The patient survey was developed based on extensive pilot testing and prior work by our team surveying breast cancer patients [6–8,11,12,18,24,25].

2.4.1. Dependent variables

We used four dependent variables for this analysis: (1) actual involvement in the breast cancer surgery decision (actual involvement), (2) match between actual and preferred involvement in this decision (match), (3) decision satisfaction, and (4) decision regret. The first dependent variable was measured using the Control Preferences Scale (CPS) developed by Degner [26] where respondents were asked to report their actual involvement

in a medical decision on a 5 point scale (see Appendix A). We recoded this variable into three categories: doctor-based, shared/collaborative, or patient-based, consistent with prior work evaluating patient involvement in breast cancer treatment decision making [6,9,27]. To evaluate match, patients were asked to report whether they felt they had too much, the right amount, or too little involvement in the surgery decision (see Appendix A). Decision satisfaction and regret were both measured using separate 5-item scales that are based on components of existing scales [28,29] (see Appendix A). Higher scores on both scales represented higher levels of both decision satisfaction and decision regret. Each scale was categorized into three levels based on tertiles representing low, medium and high amounts of decision satisfaction and regret, respectively. For logistic regression, these variables were dichotomized. For decision regret, 1 = a lot of regret vs. 0 = none or some regret. Decision satisfaction was reverse-coded to allow for direct comparison with decision regret: 1 = a lot of decision dissatisfaction vs. 0 = none or some dissatisfaction. Applying different categorizations of decision dissatisfaction and regret did not significantly alter the results.

2.4.2. Patient-related independent variables

Our primary independent variable was patient race/ethnicity which we categorized into four groups: (1) Latina-Spanish preferent (L-SP), (2) Latina-English preferent (L-EP), (3) African-American, and (4) Caucasian (C). The determination of whether a Latina respondent was Spanish or English preferent was made based on an algorithm used to assess language preference and degree of acculturation, developed by Marin and colleagues and used to measure degree of Latina acculturation [21,30].

Other demographic variables included age, education (less than high school, high school graduate, some college or more), and marital status (married, not married). We evaluated age both as a continuous and categorical (29–44, 45–64, 65–79) variable. The clinical variables used in the analysis were from the SEER record and included the tumor size in centimeters, tumor histology (well differentiated, moderately differentiated, poorly differentiated or unknown) and tumor behavior (DCIS or invasive). We chose these variables because this information is generally available at the time of surgery consultation, while pathologic stage is not available until after the biopsy [31]. We also evaluated type of surgical treatment received (mastectomy vs. BCS).

2.4.3. Mechanistic variable(s)

We included three variables to assess possible underlying mechanisms for associations between race/ethnicity and decision outcomes. These included a measure of health literacy, need for translation services, and whether women reported having a family member or friend with them during their surgical consultation(s). These measures were included based on research suggesting that health literacy, need for translation, and involvement of friends/family are particularly important to Latina women making health-related treatment decisions [1,2,18,32,33]. Our health literacy measure was developed from two questions in the patient survey reflecting how often respondents had (1) trouble understanding written information about breast cancer and (2) someone help them read written information from the hospital or clinic. These measures were combined to create a three-level measure of health literacy based on tertiles, low, moderate or high. Need for translation and having someone present were categorized as yes vs. no.

2.5. Analysis

We first generated descriptive statistics for the variables. We then calculated an adjusted proportion of women in each of the

decision outcome categories by race/ethnicity, controlling for other demographic and clinical variables. We compared differences between racial/ethnic groups for each decision outcome using Wald tests. Point estimates were adjusted for design effects by using a sample population weight that accounted for differential selection by race, ethnicity, and non-response.

2.5.1. Analysis for involvement in decision making

We conducted multinomial logistic regression for both of our three-level dependent variables, actual involvement and match. For the first model – patient actual involvement in the surgery decision – we used the shared decision as the base category (i.e., reference category). We regressed the 3-level actual involvement outcome on all variables described above in a forward stepwise manner: (1) race/ethnicity, plus other demographic and clinical variables, (2) race/ethnicity, demographics, clinical variables, plus mechanistic variables. For the second model – match between preferred and actual involvement in the surgery decision – we used the right amount of involvement as the reference category. We followed the same procedures as in the first model. For each model, we also conducted a Hausman test for independence of irrelevant alternatives (IIA test) to ensure that our three-level comparison for each outcome was correctly specified [34].

2.5.2. Analysis for decision dissatisfaction and decision regret

We conducted logistic regression of decision dissatisfaction and decision regret following the steps described for the models above. All analyses were conducted in STATA version 10.0 for Windows [35].

3. Results

The final analytic sample size for this analysis was 925 patients with stage 0, I, II, or IIIa and no clinical contraindications to BCS. The mean time between the date of definitive surgical treatment and response to the survey was 9 months. There were no significant differences in tumor behavior (DCIS vs. invasive) or treatment received by race/ethnicity (Table 1). About 18% of all women received mastectomy. About two-thirds of women reported that they had completed radiation and chemotherapy treatment by the time they participated in the survey.

3.1. Decision outcomes

Overall, 37% of women reported a shared surgical treatment decision, 36% reported a patient-based decision, and 27% reported a surgeon-based decision. The majority (93%) reported a match between actual and preferred involvement in the breast cancer surgery decision, while 3% reported having too much involvement and 4% reported having too little. Thirty three percent of the sample reported having high decision satisfaction, while 38% had moderate satisfaction and 30% had low decision satisfaction (i.e., high decision dissatisfaction). About 39% had a lot of decision regret, 30% a moderate amount of regret and another 31% reported very little regret.

3.2. Patient characteristics

The race/ethnic distribution of the sample was: 25.2% Latina-SP, 20.6% Latina-EP, 24% African-American, 26.1% Caucasian and 4.1% other. For purposes of these analyses those indicating 'other' race/ethnic group were excluded ($N = 48$). The mean age of patients was 59 years (range 29–79). Table 1 shows the proportion of women with different demographic and clinical factors by race/ethnicity. Latina women, both Spanish and English preferent, were sig-

Table 1
Characteristics of the patient sample by race/ethnicity (N = 877)^a

	Latina-SP (N = 196)	Latina-EP (N = 177)	African-American (N = 227)	Caucasian (N = 265)
Demographics				
Mean age (%)	55 (25–80)	56 (29–80)	57 (25–80)	60 (31–81) [†]
Education				
Less than H.S.	72	21	9	4
H.S. graduate	17	20	17	18
Some college or more	11	59	74	78 [*]
Marital Status				
Not married	35	42	60	37
Married/partnered	65	58	40	63 [*]
Clinical variables				
Mean tumor size in cm	2.2 (1.7)	2.2 (1.8)	2.2 (1.9)	2.1 (1.8)
Tumor differentiation				
Well/moderate	50	56	48	60
Poor/undifferentiated	40	38	42	33
Missing	11	6	10	7
Tumor behavior				
DCIS	21	18	18	21
Invasive	79	82	82	79
Surgical treatment				
Mastectomy	17	19	12	13
BCS	83	81	88	87
Mechanistic variables				
Health literacy				
Low	33	4	3	3
Moderate	50	20	24	17
High	16	76	74	81 [*]
Translation				
Did not need	11	94	98	99
Family or friend	36	5	2	<1
Doctor or staff	52	2	0	<1
Had someone with you for treatment discussions	78	76	72	70

^a Stage 0, I, II and IIIa and those without clinical contraindication to BCS included, those of “other” race/ethnicity excluded (N = 48).

^{*} $p < 0.001$; [†] $p < 0.05$ for differences between racial/ethnic groups.

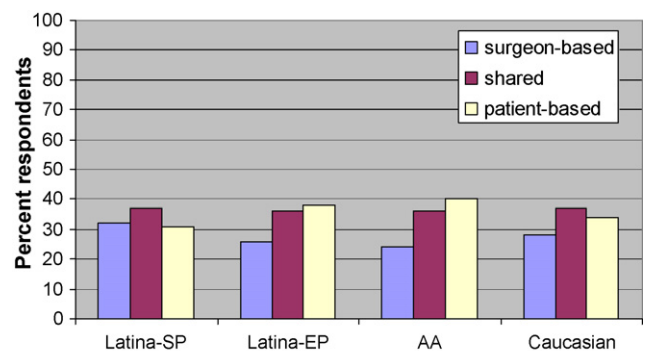
nificantly younger than Caucasian women ($p < 0.001$). Latina-SP women were significantly less likely to have some college or more education compared to other groups ($p < 0.001$). Latina-SP women were significantly more likely to have low health literacy as measured in our study than any of the other racial/ethnic groups (28.1%, 8.0%, 6.2%, and 4.5% for Latina-SP, Latina-EP, AA and Caucasian women, respectively, $p < 0.001$). As expected, Latina-SP women used more translation services than other racial/ethnic groups. About three-quarters of all women reported having someone with them during treatment discussions.

3.3. Decision outcomes by race/ethnicity

Fig. 1 provides the adjusted proportion of respondents reporting each of the three categories of actual involvement (surgeon-based, shared, patient-based) by racial/ethnic group, controlling for demographic and clinical factors. Latina-SP women were slightly less likely to report a patient-based decision than the other groups ($p < 0.10$). We also found that Latina-SP women were slightly more likely to report too little involvement compared to other groups (results not shown). Fig. 2 shows the proportion of women in each racial/ethnic group who reported high decision dissatisfaction and/or a lot of decision regret. Latina-SP women reported having both high dissatisfaction and a lot of regret significantly more often than women of other racial/ethnic groups ($p < 0.001$).

3.4. Factors associated with decision dissatisfaction and regret

Tables 2 and 3 provide the logistic regression results for correlates of high decision dissatisfaction (Table 2) and a lot of decision regret (Table 3). The first column of both tables provides the unadjusted results for race/ethnicity. The second column provides the results, controlling for other demographic and clinical factors, and the third column shows results controlling for the mechanistic variables.



[†] percentages adjusted for age, education, marital status and clinical factors

Fig. 1. Actual decision involvement by race/ethnicity.

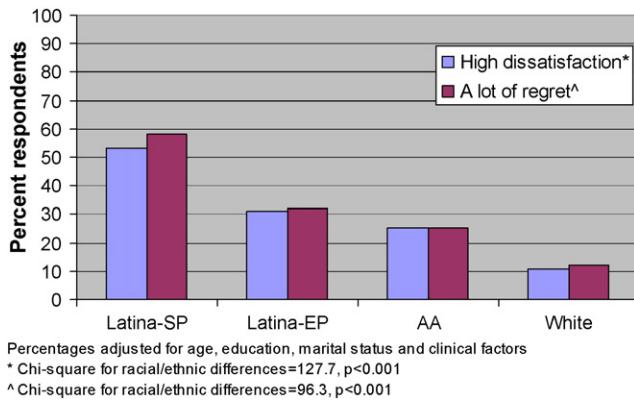


Fig. 2. Decision dissatisfaction and regret, by race/ethnicity.

As seen in Tables 2 and 3, without adjusting for other factors, Latina-SP women were 8.7 times as likely as Caucasian women to report high levels of decision dissatisfaction and 9.4 times as likely to report decision regret. The unadjusted column shows that Latina-EP and African-American women were also significantly more likely than Caucasian women to report high decision dissatisfaction and regret ($p < 0.01$). When other factors were controlled, Latina-SP women continued to be the most likely to report high decision dissatisfaction and regret though the odds were reduced in both cases (OR: 5.6; 95% CI 3.2–9.8 for dissatisfaction; OR: 5.6; 95% CI 3.2–9.9 for decision regret) compared to Caucasian women. The other racial/ethnic groups

were also more likely than Caucasian women to report dissatisfaction and regret controlling for other factors ($p < 0.05$ across racial/ethnic groups). While women with less than a high school education were more likely than those with some college to report decision dissatisfaction (OR: 1.8; 95% CI 1.1–2.8), there was no significant association between low education and decision regret. However, including education in the model did reduce the difference in decision regret between Latina-SP and Caucasian women (unadjusted OR: 9.4 vs. adjusted OR: 5.6) None of the clinical variables, including type of surgical treatment, were significantly associated with high decision dissatisfaction or regret.

The third column of both tables shows the results for race/ethnicity when controlling for the three mechanistic variables. Women with low health literacy were significantly more likely than those with high health literacy to report both decision dissatisfaction and regret (OR: 5.6; 95% CI 2.9–11.1 for dissatisfaction; OR 3.5; 95% CI 1.8–7.1 for regret). Those with moderate health literacy were also more likely to report dissatisfaction and regret ($p < 0.01$) than those with high literacy. Having someone with you during treatment discussions was negatively associated with decision dissatisfaction (OR: 0.65; 95% CI 0.44–0.96); while it was also negatively associated with regret this association was not significant (Table 3). Translation was not associated with either dissatisfaction or regret. Although including the mechanistic variables, specifically health literacy, did not attenuate the association between race/ethnicity and decision outcomes, it did significantly reduce differences in decision regret between Latina-SP and Caucasian women (from an adjusted OR of 5.6 to an adjusted OR of 4.1 including mechanistic variables).

Table 2

Logistic regression of decision dissatisfaction ($N = 877$)

	Unadjusted OR (95% CI)	Adjusted OR ^a (95% CI)	Adjusted OR ^a (95% CI)
Race/ethnicity			
Latina-SP	8.7 (5.5, 13.6)	5.7 (3.2, 9.8)	5.5 (2.9, 10.5)
Latina-EP	3.6 (2.3, 5.8)	3.1 (1.9, 5.0)	3.8 (1.6, 5.1)
African-American	2.3 (1.5, 3.7)	2.2 (1.4, 3.6)	2.1 (1.3, 3.4)
Caucasian	1.00	1.00	1.00
Education			
Less than high school		1.8 (1.2, 2.8)	1.4 (0.88, 2.3)
High school graduate		1.4 (0.97, 2.2)	1.3 (0.97, 1.1)
Some college or more		1.00	1.00
Health literacy			
Low			5.6 (2.9, 11.1)
Moderate			2.3 (1.6, 3.3)
High			1.00
Having someone with you			0.65 (0.44, 0.96)

^a Controlling for age, marital status, clinical factors, and translation.

Table 3

Logistic regression of decision regret ($N = 877$)

	Unadjusted OR (95% CI)	Adjusted OR ^a (95% CI)	Adjusted OR ^a (95% CI)
Race/ethnicity			
Latina-SP	9.4 (5.7, 14.9)	5.6 (3.1, 9.9)	4.1 (2.2, 8.0)
Latina-EP	3.1 (1.9, 5.1)	2.6 (1.6, 4.4)	2.0 (1.2, 3.7)
African-American	2.2 (1.4, 3.6)	2.0 (1.2, 3.3)	1.8 (1.1, 3.0)
Caucasian	1.00	1.00	1.00
Health literacy			
Low			3.5 (1.8, 7.1)
Moderate			2.1 (1.4, 3.1)
High			1.00
Having someone with you			0.72 (0.43, 1.1)

^a Controlling for age, education marital status, clinical factors, and translation.

4. Discussion and conclusion

4.1. Discussion

To our knowledge, this is the first analysis of breast cancer treatment decision making in a large population-based sample with substantial representation by Latinas, especially with low acculturation. Our results are consistent with what has been suggested in previous work. In one of the first papers about breast cancer treatment decision making to include Latinas, Maly et al. [2] found that Latina ethnicity was negatively associated with the provision of interactive information support by physicians (i.e., provision of information by physician with elicitation of patient feedback). This study also found that racial/ethnic minority patients more often preferred interpersonal sources of information to written information, yet were less likely than Caucasians to have received this type of interaction [2]. Another paper by Maly et al. [33] also showed that interactive informational support from providers could serve as a mechanism for reducing disparities in informed decision making, such as those seen in our results. A small qualitative study found that although Latina breast cancer patients perceived the physician–patient interaction to be an important element of quality care, Latinas had considerable distrust regarding information received about breast cancer from providers [36]. These results suggest that providers should try to convey information in a culturally acceptable manner.

While Latinas in our study reported the same amount of shared decision making as other groups, they were slightly more likely to report a mismatch between actual and preferred involvement. Other research has shown that this match is important for achieving decision and treatment satisfaction [6,7,10]. Our results suggest that matching preferred to actual involvement may be especially important for Latinas with low acculturation. Prior work by our team, and others, has found that patient–physician communication was associated with achieving this match [7,9], providing further evidence to support that the provider plays an important role in ensuring patients obtain their desired amount of involvement in decisions.

A possible explanation for the findings related to poor decision outcomes in the less acculturated, Latina-SP, group lies with the decision process; specifically with language barriers and poor communication with providers regarding treatment options. Studies have demonstrated the importance of physician–patient communication in general [37,38], and for breast cancer treatment specifically [9,39–41]. However, none have included sufficient samples of Latinas to evaluate the impact of language and/or culture on decision making. Many studies have found that language and acculturation are important factors in Latina patients' utilization of services, such as cancer screening and diabetes care [42–44]. It would follow that these issues are important to Latinas faced with breast cancer treatment decisions. Only two papers to date have assessed the impact of acculturation on breast cancer treatment decision making [17–19]. In a prior study with fewer Latinas, our team found that less acculturated Latinas had the highest odds of decision dissatisfaction [18]. Maly et al. [17] found that the role of family in decision making was greatest for Latinas with low acculturation. We found in this study that many women reported including others in treatment discussions. While we did not specifically ask whether a family member helped with treatment decision making, we did find that having someone with you during treatment discussions was associated with better decision outcomes across race/ethnicity. This result is consistent with other research documenting the importance of companions in cancer communications [45].

Ongoing work by our team provides another possible reason for the poor decision outcomes reported by less acculturated Latinas, supporting the idea that Latinas may be less satisfied with the decision making process compared to other groups. We found that despite reporting receiving similar amounts of information about surgical treatments as Caucasians, Latinas with low acculturation reported a strong desire for more information [46]. These results, coupled with those above, suggest that additional effort may be needed by clinicians to ensure that information is understandable and culturally appropriate and improve the decision making process for all breast cancer patients.

Our limited measure of health literacy was independently associated with decision dissatisfaction and regret, and slightly reduced the association between race/ethnicity and decision regret. Thus, despite Latina-SP women having significantly less education than other women, low literacy did not fully account for all poor decision outcomes. Simply directing providers to target discussion to a lower literacy level may not be sufficient to improve decision satisfaction among Latina-SP women. Moreover, a recent study found that providers overestimated the literacy levels of their patients, particularly for minority patients, suggesting a possible source of disparities in certain health outcomes [47]. However, as recommended by the Institute of Medicine, language and literacy issues need to be addressed by providers in any healthcare decision [48].

Our study has some limitations. First, the measures used in our analysis came from patient self-report and may be subject to recall bias. Second, the study was cross sectional and we can only determine associations between independent variables and our outcomes of interest. Third, our study was conducted in one geographic location and despite the racial/ethnic diversity may not be generalizable to other women with breast cancer. Though we did achieve high representation of Latinas, we were not able to evaluate decision making among Latina sub-groups. Our outcomes may have also been subject to measurement error. Our measures may not be best suited for evaluating decision making among Latinas. For example, the Control Preferences Scale does not allow for the influence of family in the decision making process. Finally, our measure of language preferences was a proxy for acculturation and further work assessing the role of culture in decision making is needed.

4.2. Conclusion

Latina women, especially those who prefer Spanish, appear to be at increased risk for poor breast cancer treatment decision outcomes. Although there were no racial/ethnic differences in tumor behavior (DCIS vs. invasive), or in subsequent treatment (mastectomy vs. BCS), Latinas in our study were significantly more likely than Caucasian patients to experience decision dissatisfaction and regret. The finding that health literacy was independently associated with poor decision outcomes indicates that this is an important contributor to poor decision outcomes among racial/ethnic breast cancer patients. Overall, our results suggest that despite similar clinical outcomes, patient experiences with decision making were very different.

4.3. Practice implications

Providers need to be aware that minority and low literacy patients, especially less acculturated Latinas, are vulnerable to poor decision outcomes. Clinicians should be attentive to patient preferences for involvement in decision making and to the inclusion of others (e.g., family) in decision making. Interventions to improve the ability of providers to communicate in a culturally

appropriate manner, and to accurately assess the health literacy of their patients, may improve the process of breast cancer treatment decision making.

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Appendix A

Latina patient perspectives about informed treatment decision making for breast cancer
Decision outcomes

I. Patient actual involvement in surgical treatment decision

(Control Preferences Scale from Degner, 1992)

Please describe how your surgical treatment decision was made (choose one):

- My doctor(s) made the surgery decision with little input from me.
- My doctor(s) made the surgery decision but seriously considered my opinion.
- My doctor(s) and I made the surgery decision together.
- I made the surgery decision after seriously considered my doctor(s) opinions.
- I made the surgery decision with little input from my doctor(s).

II. Match between actual-preferred involvement

Thinking back over your surgical breast cancer decision, would you say:

- I wish I had been more involved in the surgical treatment decision.
- My level of involvement was about right for me.
- I wish my surgeon had been more involved in the surgical treatment decision.

III. Decision satisfaction 5-item scale

(All 5-point Likert Scale response options from strongly agree to strongly disagree)

- I am satisfied I was adequately informed about the issues important to the decision about what kind of surgery to have.
- I am satisfied with the decision about what kind of surgery to have.

- I wish I had given more consideration to other surgical treatment options.
- I would have liked more information when the decision about surgery was made.
- I would like to have participated more in making the decision about what kind of surgery to have.

IV. Decision regret 5-item scale

(All 5-point Likert Scale response options from strongly agree to strongly disagree)

If I had to do it over . . .

- I would make a different decision about what type of surgery to have.
- I would choose a different surgeon for my surgery.
- I would take more time to make decisions about my treatment.
- I would consult more doctors about my treatment before making a decision.
- I would do everything the same.

Conflict of interest

The authors do not have any conflict of interest to disclose, including any financial, personal or other relationship within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, this work.

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