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### Permalink

<https://escholarship.org/uc/item/3z72858d>

### Journal

Patient Education and Counseling, 94(1)

### ISSN

0738-3991

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### Publication Date

2014

### DOI

10.1016/j.pec.2013.09.005

Peer reviewed



Published in final edited form as:

*Patient Educ Couns.* 2014 January ; 94(1): 83–89. doi:10.1016/j.pec.2013.09.005.

## Satisfaction with treatment decision-making and treatment regret among Latinas and non-Latina whites with DCIS

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### Abstract

**Objective**—To examine differences in treatment decision-making participation, satisfaction, and regret among Latinas and non-Latina whites with DCIS.

**Methods**—Survey of Latina and non-Latina white women diagnosed with DCIS. We assessed women's preferences for involvement in decision-making, primary treatment decision maker, and participatory decision-making. We examined primary outcomes of satisfaction with treatment decision-making and treatment regret by ethnic-language group.

**Results**—Among 745 participants (349 Latinas, 396 white) Spanish-speaking Latinas (SSL) had the highest mean preference for involvement in decision-making score and the lowest mean participatory decision-making score and were more likely to defer their final treatment decision to their physicians than English-speaking Latinas or whites (26%, 13%, 18%,  $p < .05$ ). SSLs reported lower satisfaction with treatment decision-making (OR 0.4; CI 95%, 0.2-0.8) and expressed more regret than whites (OR 6.2; CI 95%, 3.0-12.4). More participatory decision-making increased the odds of satisfaction (OR 1.5; CI 95%, 1.3-1.8) and decreased the odds of treatment regret (OR 0.8; CI 95%, 0.7-1.0), independent of ethnicity-language.

**Conclusion**—Language barriers impede the establishment of decision-making partnerships between Latinas and their physicians, and result in less satisfaction with the decision-making process and more treatment regret.

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Author Disclosure Statement: Dr. Hwang wishes to disclose research funding from Merck & Co., Inc. Drs. López, Kaplan, Livaudais, Nápoles, and Karliner have no potential conflicts to disclose.

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**Practice Implications**—Use of professional interpreters may address communication-related disparities for these women.

### Keywords

decision-making; ductal carcinoma in situ; doctor-patient communication; language barriers; Latina; health disparities

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## 1. Introduction

Ductal carcinoma in situ (DCIS) is a potential precursor to invasive breast cancer. It is highly treatable and has a 10-year survival rate of 96-98%(1). Both mastectomy and breast conserving surgery (BCS) are clinically appropriate surgical treatments for DCIS and provide equal survival benefits, yet differ in rates of local and contralateral recurrence and postoperative sequelae.(1, 2) Because of these treatment options as well as the importance of distinguishing DCIS from invasive cancer while offering treatments almost identical to those offered for invasive cancer, the treatment decision-making process for DCIS is complex and patient preferences are expected to play a key role in treatment decisions.(3) DCIS patients, however, are not always well informed about their diagnosis or treatment choices.(4-7) Latinas with breast cancer have been found to be less informed about their diagnosis and less likely to seek or receive information about treatment options than whites.(6, 8) For some Latinas, language barriers may impede physicians' ability to discuss in-depth important treatment-related information, potentially impacting the ability of those with limited English proficiency (LEP) to adequately assess their treatment choices.(9)

Interactive informational support from physicians about breast cancer treatment has been associated with greater perception of choice and more involvement in decision-making, enabling patients to ask more questions and feel more in control.(5, 10-12) Patient involvement in the final treatment decision has been associated with increased satisfaction with both the decision-making process and with breast cancer care.(5, 11, 13) A mismatch between patients' desired and actual level of involvement in decision-making has been found to result in lower levels of satisfaction with the decision-making process and greater regret of treatment choice, particularly among Spanish-speaking Latinas.(14-16) However, these prior studies have largely focused on invasive breast cancer, and although some have included DCIS patients, their numbers have been too small to analyze separately from those with invasive cancer.

Acculturation, education and literacy have also been linked to patients' involvement in the decision-making process. Less acculturated Latinas have been found to be less involved in the final treatment decision-making for invasive breast cancer and DCIS, often deferring the final decision to their physicians or to potentially less informed relatives or friends.(6, 15, 17) Low educational attainment and low health literacy have also been associated with less involvement in breast cancer decision-making and dissatisfaction with the decision-making process among women with invasive disease.(14, 15, 18-20) Without critical treatment-related information, Latinas may not feel qualified to make their own treatment decisions and may not be able to take on a more participatory role in decision-making.(12) In prior studies that have focused on who makes the final treatment decision, Latinas have been found to have lower levels of involvement in decision-making than whites, despite a preference for a more participatory role.(6, 12, 21)

Previous studies have yet to assess, in the context of DCIS, the extent to which physicians engage patients in the decision-making process and whether greater patient involvement in the process of treatment decision-making influences patient satisfaction, regardless of who

makes the final decision. Nor have they assessed whether the decision-making process is associated with regret about the decision once it has been made.

The overall aim of this study was to examine differences in treatment decision-making participation and satisfaction among Latinas and non-Latina whites with DCIS. We investigate the degree to which patients and physicians collaborate in the decision-making process and assess the impact of this patient-physician collaboration on satisfaction with the decision-making process and regret related to treatment decisions.

## 2. Methods

### Sample

Women were sampled from eight California Cancer Registry (CCR) regions representing 35 of 58 counties in California. Inclusion criteria were female, aged 18 or older, self-identified English or Spanish speaking Latina or non-Latina white, diagnosed with DCIS between 2002 and 2005, and without a subsequent diagnosis of invasive breast cancer. Women were excluded if a physician recommended that they not participate in the study or in case of significant cognitive or mental disability as judged by the interviewer.

All Latina women were sampled within each region and county. White women, who significantly outnumbered Latinas, were randomly sampled and matched to the Latina cases by age (within five-year increments), diagnosis period (within six-month intervals), and county of diagnosis. A more detailed description of participant sampling is described elsewhere. (22)

### Data collection

Study recruitment took place between January 2005 and September 2006. Physicians for each patient listed in the registry were mailed a letter explaining the study and asking them to identify patients we should not contact. Eligible women were mailed a letter of invitation along with a refusal postcard, and if they did not return the postcard, were contacted by telephone. Telephone interviews were conducted in English or Spanish, according to the participant's preference and took place approximately 24 months post-diagnosis. Participants received a \$20 gift certificate for completing the interview. Informed consent was obtained from all participants and all study procedures were approved by the UCSF Committee on Human Research (CHR).

### Dependent Variables

Our two dichotomous dependent variables of interest were: 1) satisfaction with the decision-making process and 2) treatment regret. We measured satisfaction with decision-making with an adaptation of two standardized scales validated for use with breast cancer patients. (5, 20, 23) Using a 5-point Likert scale for each item (strongly disagree to strongly agree) we measured agreement with the following 8 items: 1) I wish I had thought more about other surgical options; 2) I wish I had more information when deciding the type of surgery; 3) I wish I had participated more when deciding on the type of surgery; 4) I wish I had more information on what to expect after the surgery ; 5) the decision made about the type of surgery was the best decision for me personally; 6) I am satisfied that the decision about the type of surgery was consistent with my personal beliefs; 7) I was given enough time to make the decision about the type of surgery; 8) I am satisfied with the amount of control I had over the decision about the type of surgery. Response options ranged from strongly disagree (1) to strongly agree (5). We created a dichotomous measure of satisfaction with decision-making (yes/no) with higher average scores (4-5) indicative of satisfaction and lower average scores (1-3) of dissatisfaction.

We measured treatment regret using a single item: “If I had to do it over again, I would make a different decision about the type of surgery.” Item responses were given on a 5-point likert scale ranging from strongly disagree to strongly agree with higher scores representing increasing regret. For our multivariate model, we created a dichotomous measure of treatment regret (yes/no) by recoding scores of 4-5 (agree somewhat/strongly) as indicative of regret and scores 1-3 (neither/somewhat/ strongly disagree) as not indicative of regret.

### Independent variables

**Preferences for involvement in decision-making**—To measure preferences for involvement in decision-making we used a previously published 6-item scale with scores ranging from 1-3 (not important at all, somewhat important, very important). Higher scores indicated greater preference for involvement.(5) The items included preferences for participating in selecting treatment, asking the physician questions, having physicians ask their preferences, feeling in control of treatment choices, and voicing opinions about treatment. The Chronbach  $\alpha$  for this scale was 0.78 in this sample.

**Primary treatment decision maker**—To assess who made most of the treatment decisions, we asked participants whether: “ your physician made most of the treatment decisions”, “ you both made the decisions together”, or “ you made most of the treatment decisions”.(24)

**Participatory decision-making**—Using the two-item Participatory Decision-making scale from the Interpersonal Processes of Care Survey (25), we asked participants how often physicians asked them if they would like help deciding on a treatment and how often physicians took into account their daily routines when deciding on a treatment plan. This was a 5-point Likert scale ranging from 1-5 (rarely to always) with higher scores indicating higher levels of participatory decision-making. The Crohnbach  $\alpha$  for this scale was 0.66 in this sample.

**Ethnicity/language**—Based on self-report, we classified participants as either non-Latina white or Latina. We further classified Latinas as English-speaking or Spanish-speaking based on their interview language, which was highly correlated with their self-reported English language ability. Our ethnicity/language indicator comprised three categories: White, English-speaking Latina, and Spanish-speaking Latina. Study participants were also administered the Short Acculturation Scale for Latinos (SASH) which measures different aspects of language including spoken, thought, use at home and use with friends. (26, 27)

### Covariates

**Demographic indicators**—Other demographic indicators included age, education (less than high school, high school/vocational, college or higher), household income (<\$20,000, \$20,001-\$40,000, > \$40,000), and insurance (public, none/unknown vs. private). Due to low numbers, participants with no insurance (n= 33) or unknown insurance (n=8) were grouped with participants with public insurance (Medicare, MediCal, Veterans’ Administration) and compared to participants with private insurance (HMO or private non-HMO).

**Surgery type**—Participants were classified into two groups: women treated with a mastectomy (n=239) or those treated with breast conserving surgery (BCS; n=503). Three women who reported no surgery were dropped from our analysis.

**Health-related indicators**—The presence of comorbidities was measured using a modified version of the Self-Administered Comorbidity Questionnaire (SCQ).(28) Patients

were also asked if they had taken adjuvant hormone therapy (tamoxifen, raloxifene, or anastrozole) as part of their treatment (yes/no).

**Language interpretation**—In addition, we assessed use of an interpreter when receiving care and type of interpretation received (family member or friend, staff, physician, professional interpreter in person or professional interpreter over the telephone).

**Analysis**—We assessed differences by ethnicity and language in our variables of interest by conducting chi-square tests and analysis of variance. We developed logistic regression models to identify factors predicting satisfaction with decision-making and treatment regret. We included in our models preferences for involvement in decision-making, primary decision maker, participatory decision-making, ethnicity/language group, other demographic indicators, surgery type, and other health-related indicators.

### 3. Results

#### Participant characteristics. (Table 1)

Seven-hundred forty-five women completed surveys (61% participation rate), with whites having a higher completion rate than Latinas (67% vs. 55%). Recruitment details have been published elsewhere. (22, 29) The mean age of the sample was 57 years (range = 47-67). Spanish-speaking Latinas were younger, had significantly lower levels of education, came from less affluent households, and were less likely to be privately insured than English-speaking Latinas and whites. There were no differences by ethnicity/language in type of surgery received. Mean time between diagnosis and interview was 23.8 months (SD 7.9).

Mean acculturation score was significantly higher among English-speaking Latinas than among Spanish-speaking Latinas (4.1 vs. 1.4,  $p < 0.001$ ) (results not shown in table). In addition, nearly all Spanish-speaking Latinas (99%) were first generation immigrants. Overall, seventy percent of Latina participants were first generation immigrants (e.g., foreign-born) and 79% of foreign-born Latinas women were Spanish-speaking. Among second generation Latinas (e.g., U.S.-born), nearly all (99%) were English-speaking. Acculturation was highly correlated with interview language and language ability ( $\rho = 0.80$ ). As a result, acculturation was not included in the final analyses.

#### Decision-making process (Table 2)

While most women reported a preference for being involved in decision-making, Spanish-speaking Latinas reported a slightly greater preference for involvement than English-speaking Latinas and whites. More than half of the women in the study reported that they had made their decisions together with their physicians (61%). Spanish-speaking Latinas were the least likely to report making decisions together with their physicians (58% Spanish-speaking Latinas vs., 68% English-speaking Latinas and 60% whites,  $p = .02$ ) and the most likely to report that the physician had made most of the treatment decisions compared to English-speaking Latinas and whites (26%, 13%, and 18%,  $p = 0.02$ ). Spanish- and English-speaking Latinas were less likely than whites to report making most of the treatment decisions alone (16%, 19%, and 22%,  $p = .02$ ). Spanish-speaking Latinas were the least likely to report participatory decision-making compared to English-speaking Latinas and whites as measured by mean scores on the Participatory Decision-making scale (3.0 vs. 3.4 and 3.2,  $p = .02$ ). Among Spanish-speaking Latinas, 69% reported having an interpreter present when discussing treatment options with their physicians. Three percent of those interpreters were professional interpreters, while 53% were either family members or friends, and 44% were either a nurse or clinic staff.

### Satisfaction with decision-making and regret; bivariate analysis

Spanish-speaking Latinas were less likely to report being satisfied with the decision-making processes than English-speaking Latinas and whites: 47% of Spanish-speaking Latinas reported satisfaction compared to 77% of English-speaking Latinas and 83% of whites,  $p < .001$ . Spanish-speaking Latinas were also most likely to report treatment regret as measured by the percent who somewhat/strongly agreed with the statement, 'if I had to do it over again, I would make a different decision about treatment' (35% Spanish-speaking Latinas vs. 7% English-speaking Latinas and 10% whites,  $p < .001$ ).

### Multivariate analysis (Table 3)

In our adjusted logistic regression models, Spanish-speaking Latinas had significantly lower odds of reporting satisfaction with decision-making than whites (OR 0.3; CI 95%, 0.2-0.6) regardless of who made most of the treatment decisions, level of involvement in decision-making, or preference for more involvement in decision-making. English-speaking Latinas were similar to whites. Lower educated women had lower odds of satisfaction than more educated women. Education and ethnicity/language effects were independent of each other. Regardless of ethnicity/language, women reporting that the physician had made most of the treatment decisions had lower odds of satisfaction compared to women reporting making decisions together with the physician (OR 0.3; CI 95%, 0.2-0.6). Similarly, women reporting a more participatory decision-making process had higher odds of satisfaction compared to women reporting a less participatory process (OR 1.4; CI 95%, 1.2-1.7).

With respect to treatment regret, in our adjusted model, Spanish-speaking Latinas had higher odds of regret compared to whites (OR 4.5; CI 95%, 2.2-9.0) and English-speaking Latinas were similar to whites. Women reporting a more participatory decision-making process had lower odds of regret than women reporting a less participatory process (OR 0.8; CI 95%, 0.7-1.0).

## 4. Discussion and Conclusion

### 4.1 Discussion

Our study uncovered ethnic-language differences in satisfaction with the decision-making process for DCIS and regret regarding the decision made. Spanish-speaking Latinas were less satisfied with the decision-making process and reported more treatment regret than English-speaking Latinas and whites. In contrast, English-speaking Latinas and whites reported levels of satisfaction and regret similar to each other. Additionally, Spanish-speaking Latinas were more likely than the other two groups to defer their treatment decisions to their physicians, despite high levels of preference for participatory decision-making. These results support the important role of language discordance as a major barrier to communication and patient-centered decision-making.

Language barriers between Spanish-speaking Latinas and their physicians may have limited the ability of their physicians to discuss treatment options with them, resulting in lower levels of participation as well as lower satisfaction with the process. This is consistent with prior research from our group in which breast cancer physicians reported worrying that LEP patients do not ask all of their questions about treatment. The physicians also reported being more directive about treatment with LEP patients compared to English-speaking patients. Those physicians who used professional interpreters reported higher rates of patient-centered communication about treatment with their non-English speaking patients.(9)

While in our study, 69% of Spanish-speaking Latinas reported having an interpreter present when discussing treatment options with their physicians, for only three percent this was a

professional interpreter. Whereas for half the interpreter was a family member. Having a family member interpret could partially explain Spanish-speaking Latinas' lower satisfaction levels, particularly if family members attempted to make decisions for the patient or failed to disclose relevant information to the patient and her physician. In the context of the nuanced decision-making required for DCIS treatment, language barriers and lack of professional interpretation place Spanish-speaking Latinas at high risk of poor communication-related outcomes, including lower satisfaction and higher regret about treatment decisions. Use of professional interpreters may enhance the information exchange between patient and physician, the participatory nature of treatment decision-making and address disparities in satisfaction for these women. (30-32)

Language preference, an indicator of acculturation level among Latinos, may also be a proxy for cultural factors.(26, 27) For Spanish-speaking Latinas, cultural values that govern social interactions and relationships with individuals perceived to be in positions of power, may influence their expectations of the patient-physician relationship and level of involvement in decision-making.(6, 14) Spanish-speaking Latinas may expect more direct guidance from their physicians during decision-making or may feel uncomfortable questioning their physicians.(6) This may be true even if their preference is to be involved in the decision-making as it was for the Spanish-speaking Latinas in our study. Given that nearly one-third of Spanish-speaking participants did not have an interpreter, language difficulties likely presented a significant barrier to communication about treatment options and decision-making.

In our study, lower educational attainment was independently associated with lower satisfaction with the decision-making process. This is consistent with previous findings the impact of education on decision-making and satisfaction for breast cancer patients.(12) Spanish-speaking Latinas had the lowest educational attainment in our study, and the combination of limited education and limited English proficiency may place these women in 'double jeopardy' for worse communication-related outcomes.

Physician participatory style was an important factor in patients' satisfaction with treatment decision-making. Regardless of ethnicity and language, our results indicate that women with DCIS who felt that they had been more involved in the treatment decisions were more satisfied and less likely to regret their decisions. Spanish speaking Latinas' preference for involvement in decision making was at least equal to if not greater than English speaking Latinas and whites. Despite this equal preference, they were the least likely to report experiencing this involvement. The mismatch between their preference to be involved and the reality of having been less active participants in their treatment decisions may well have contributed to their lower level of satisfaction and higher level of treatment regret than English speaking Latinas and whites. Taken together, our results present a consistent picture suggesting that factors such as communication and language barriers, rather than patient preference, are likely to explain these differences in patient experience.

Prior studies of breast cancer patients have highlighted the important role that physicians play in their patients' perceptions of choice and their level of participation in decision-making (5, 11, 12) and our findings confirm this relationship in the context of DCIS. Thus, it is incumbent upon physicians to elicit patients' preferences for involvement in treatment decision-making, (16) and then to make sure to involve patients in treatment decisions whenever possible and appropriate. This is particularly true for LEP and less educated patients who may not be as assertive, but have at least as high a likelihood of wanting to participate in decision-making as their English-speaking and better educated counterparts.



**Study limitations**—Although this was a population-based study representing women from 35 counties in California, we acknowledge several limitations. This was a cross-sectional study; a one-time snapshot of women’s experiences with DCIS, taken approximately 24 months after treatment due to the amount of time required for the CCR to process new cases of breast cancer. Therefore, recall of decision-making processes as well as satisfaction may have fluctuated over time or have been influenced by more recent experiences. While this may be a limitation inherent to any study focused on participant perceptions, the potential for a change in perception does not render it less valid. On the contrary, it is a true measure of how a participant feels about the event at that particular time of their life. Because this was a cross-sectional study, no causality between decision-making behaviors and satisfaction or regret can be inferred. Additionally, we report patient perceptions of participation in decision-making, not data from direct observations. However, treatment regret, by its nature can only be assessed after the passage of time.

#### 4.2 Conclusion

Despite reported preferences for involvement in decision-making, Spanish-speakers were less engaged in decision-making about treatment for their DCIS than their English-speaking Latina and white counterparts. Language barriers not only impede the establishment of decision-making partnerships between Latinas and their physicians, but also result in less satisfaction with the decision-making process and more treatment regret. Provision of professional interpreters would likely help to alleviate discrepancies between Spanish-speaking Latinas’ desires to participate in treatment decision-making and their perceived lack of participation.

#### 4.3 Practice Implications

Our study suggests that the key to successful decision-making lies in the partnership established between patients and their physicians. Much of the responsibility for establishing this partnership lies with physicians, as well as with the health systems that are charged with providing patients with access to professional interpreters. Both physicians and patients would also benefit from physician training in how to work with interpreters and communicate across language and cultural barriers, and from the development of decision-support aids for Spanish-speakers that take into account health literacy, language, and cultural factors.

### Acknowledgments

This research was conducted with the support of the California Breast Cancer Research Program (grant number 9PB-0157) and the National Institute for Aging, through a Diversity Supplement to the Center for Aging in Diverse Communities (grant number P30-AG15272). The collection of cancer incidence data used in this study was supported by the California Department of Public Health as part of the statewide cancer reporting program mandated by California Health and Safety Code Section 103885; the National Cancer Institute’s Surveillance, Epidemiology and End Results Program under contract N01-PC-35136 awarded to the Northern California Cancer Center, contract N01-PC-35139 awarded to the University of Southern California, and contract N02-PC-15105 awarded to the Public Health Institute; and the Centers for Disease Control and Prevention’s National Program of Cancer Registries, under agreement #U55/CCR921930-02 awarded to the Public Health Institute. Dr. Karliner’s time was supported by American Cancer Society (grant MRSMT-06-253-01). The ideas and opinions expressed herein are those of the author(s) and endorsement by the State of California, Department of Public Health, the National Cancer Institute, and the Centers for Disease Control and Prevention or their contractors and subcontractors is not intended nor should be inferred. We wish to thank Susan Duffey and Jessica Quinn for their editing and project assistance.

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**Table 1**

Participant characteristics of women treated for DCIS: Differences by ethnicity-language

	Ethnicity/Language			Total N=742
	Latina (Spanish) N=193	Latina (English) N=155	White N=394	
<b>Demographics</b>				
Age				
Less than 50	65 (34%)	44 (28%)	112 (28%)	221 (30%)
50-60	69 (36%)	53 (34%)	130 (33%)	253 (34%)
>60	59 (31%)	58 (37%)	152 (38%)	269 (36%)
Education level***				
Less than high school	114 (60%)	21 (14%)	10 (2%)	145 (20%)
High school/Vocational	37 (20%)	51 (33%)	73 (19%)	161 (22%)
Any college or higher	38 (20%)	81 (53%)	308 (79%)	427 (58%)
Income ***				
\$20,000	67 (35%)	24 (16%)	22 (6%)	113 (15%)
\$20,001-\$40,000	41 (21%)	38 (25%)	46 (12%)	125 (17%)
>\$40,000	29 (15%)	71 (46%)	258 (66%)	360 (48%)
Don't know	56 (29%)	22 (14%)	68 (17%)	146 (20%)
Geographical region**				
Bay Area	34 (18%)	41 (27%)	128 (33%)	203 (27%)
Sacramento & Central CA	41 (21%)	39 (25%)	71 (18%)	151 (20%)
Los Angeles & Tri-Counties	72 (37%)	41 (26%)	114 (29%)	227 (31%)
Riverside & San Bernardino	27 (14%)	25 (16%)	48 (12%)	100 (14%)
San Diego	19 (10%)	9 (6%)	33 (8%)	61 (8%)
Insurance ***				
Private insurance	88 (46%)	119 (76%)	326 (82%)	533 (72%)
<b>Surgery type</b>				
Mastectomy	67 (35%)	48 (31%)	124 (32%)	239 (32%)
BCS	126 (65%)	107 (69%)	270 (69%)	503 (68%)
<b>Health related indicators</b>				
Comorbidities				
Mean (SD)	1.8 (1.7)	2.0 (1.7)	1.7 (1.6)	1.8 (1.6)
Adjuvant hormone therapy**	103 (53%)	77 (50%)	168 (43%)	348 (50%)

\* p&lt;.05,

\*\* p&lt;.01,

\*\*\* p&lt;.001

**Table 2**

Differences in decision-making among women treated for DCIS by ethnicity-language

	<b>Latina (Spanish) N: 177-181<sup>†</sup></b>	<b>Latina (English) N:135-155<sup>†</sup></b>	<b>White N:357-395<sup>†</sup></b>	<b>Total</b>
Preferences for involvement in decision making (1-3) <sup>*</sup>	3.0 (0.1)	2.9 (0.3)	2.9 (0.2)	2.9 (0.2)
Mean (SD)				
Primary treatment decision-maker <sup>*</sup>				
Doctor	48 (26%)	20 (13%)	69 (18%)	137 (19%)
Patient	30 (16%)	30 (20%)	89 (23%)	149 (20%)
Both	110 (59%)	102 (67%)	237 (60%)	449 (61%)
Participatory decision making (1-5) <sup>*</sup>				
Mean (SD)	3.0 (1.5)	3.4 (1.4)	3.2 (1.3)	3.2 (1.4)

\* p&lt;.05,

\*\* p&lt;.01,

\*\*\* p&lt;.001

<sup>†</sup> Range of denominator varies according to the number of incomplete response for some questions

**Table 3**

Satisfaction with decision-making process and treatment regret among women treated for DCIS

	<b>Satisfaction with decision-making</b>	<b>Treatment Regret</b>
	<b>OR (SD) N:626</b>	<b>OR(SD) N: 645</b>
<b>Race/Ethnicity</b> (ref white)		
Latina-Spanish	<b>0.3 (0.2-0.6)</b>	<b>4.5 (2.2-9.0)</b>
Latina-English	0.9 (0.5-1.6)	0.7 (0.3-1.5)
<b>Education</b> (ref. college or higher)		
Less than high school	<b>0.4 (0.2-0.7)</b>	1.8 (0.9-3.8)
High school or vocational	<b>0.6 (0.3-1.0)</b>	1.3 (0.7-2.4)
<b>Preferences for involvement in decision making</b> (increasing preference for involvement)	0.5 (0.2-1.5)	0.6 (0.2-1.6)
<b>Primary treatment decision-maker</b> (ref. both)		
Doctor	<b>0.3 (0.2-0.6)</b>	1.2 (0.6-2.2)
Patient	0.8 (0.5-1.4)	1.6 (0.9-2.9)
<b>Participatory decision making</b> (increasing involvement)	<b>1.4 (1.2-1.7)</b>	<b>0.8 (0.7-1.0)</b>

OR controlled for age, income, insurance, treatment type and comorbidities