


# Communication and Shared Decision Making in the Breast Cancer Treatment Consultation: A Comparative Analysis of English- and Spanish-Speaking Patients

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## Abstract

**Background.** Communication in the breast cancer treatment consultation is complex. Language barriers may increase the challenge of achieving patient-centered communication and effective shared decision making. **Design.** We conducted a prospective cohort study among Spanish- and English-speaking women with stage 0 to 3 breast cancer in two urban medical centers in the Midwestern United States. Patient centeredness of care and decisional conflict were compared between Spanish- and English-speaking participants using the Interpersonal Processes of Care (IPC) and Decision Conflict Scale (DCS), respectively. Clinician behaviors of shared decision making were assessed from consultation audio-recordings using the 12-item Observing Patient Involvement in Decision Making (OPTION) scale. Multivariate regression analyses were conducted to control for differences in baseline characteristics and clinician specialty. **Results.** Fifteen Spanish-speaking and 35 English-speaking patients were enrolled in the study. IPC scores (median, interquartile range [IQR]) were higher (less patient centered) in Spanish- versus English-speaking participants in the domains of *lack of clarity* (2.5, 1-3 v. 1.5, 1-2),  $P = 0.028$ ; *perceived discrimination* (1.1, 1-1 v. 1.0, 1-1),  $P = 0.047$ ; and *disrespectful office staff* (1.25, 1-2 v. 1.0, 1-1),  $P < 0.0005$  (Wilcoxon rank-sum test). OPTION scores (median, IQR) were lower in Spanish- versus English-speaking participants (21.9, 17.7-27.1 v. 31.3, 26.6-39.6),  $P = 0.001$  (Wilcoxon rank-sum test). In multivariate analysis, statistically significant differences persisted in the IPC *lack of clarity* and *disrespectful office staff* between Spanish- and English-speaking groups. **Conclusions.** Our findings highlight challenges in cancer communication for Spanish-speaking patients, particularly with respect to perceived patient centeredness of communication. Further cross-cultural studies are needed to ensure effective communication and shared decision making in the cancer consultation.

## Keywords

Breast Neoplasm, Communication, Health Numeracy, Hispanic Americans, Referral and Consultation

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Breast cancer treatment consultations involve complex information, presenting a challenge for providers in communicating effectively and participating in a shared decision making (SDM) process.<sup>1</sup> Numeric information including the probabilities of recurrence, relative treatment

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efficacy, and genomic data pertaining to prognosis may be part of the treatment consultation.<sup>2,3</sup> Understanding and applying numeric information requires skills in number sense and arithmetic, use of tables and graphs, and concepts of probability and statistics.<sup>4-6</sup> The interpretation of numeric terms can differ across language and cultures,<sup>7</sup> with potential barriers to communication further complicated by the need for translators.<sup>8</sup>

The breast cancer treatment consultation often incorporates both information sharing and SDM. In a framework of SDM, a high-quality decision requires that patients are aware of a decision choice, knowledgeable about decision options and expected outcomes, consider their values and preferences, and engage in a deliberative decision making process with their provider.<sup>9</sup> A SDM process is posited to lead to increased knowledge, value-aligned decisions, adherence to a treatment plan, and decreased decisional regret.<sup>2,10</sup> Effective communication and SDM have been associated with increased quality of life for breast cancer survivors.<sup>11,12</sup> However, there are limited studies of patient-centered communication and SDM in cancer care in cross-cultural and non-English-speaking populations.<sup>13-15</sup> The objectives of this study are to compare the breast cancer treatment consultation experience between Spanish- and English-speaking patients with respect to patient-centered communication and provider behaviors of SDM.

## Methods

### *Study Design*

As part of a parent study, we conducted a prospective cohort study of communication and decision making for women with a new diagnosis of breast cancer. The focus of the parent study was to evaluate the impact of measuring and reporting patient health numeracy level to the provider prior to the consultation and evaluating its

impact on the quality of communication. Participants completed baseline assessments prior to a treatment consultation and a follow-up survey assessment 1 week after the consultation.<sup>16</sup>

### *Study Protocol*

Participants were required to be Spanish- or English-speaking women with a new diagnosis of stage 0 to 3 breast cancer and receiving treatment at one of two participating academic medical centers in the Midwestern United States. Exclusion criteria included cognitive impairment as determined in the medical chart review. The treating clinicians in specialties of medical, radiation, or surgical oncology were enrolled in the study. Eligible patients were identified by the breast cancer clinic teams and information about the study was placed in their education packet received at the time of diagnosis. Enrollment occurred after the patient had received their diagnosis and prior to a scheduled treatment consultation in radiation oncology, general surgery, or medical oncology. Professional interpreters were available for the consultation for all Spanish-speaking participants. Interested patients contacted the study research assistant and, if eligible, were enrolled. Participants were compensated for their time with a \$50 incentive. Clinicians and patient participants signed an informed consent. The protocol was approved by the institutional review board at the participating sites.

Baseline measures were assessed directly preceding the consultation. A follow-up patient survey was conducted 1 week following the consultation. Patients were evaluated with the Computer Adaptive Test version of the Numeracy Understanding In Medicine Instrument (CAT-NUMi) and results were given to the clinician prior to the consultation.<sup>17</sup> As the consultation was audio-recorded for the parent study, informed consent was obtained from the patients, providers, and significant others that were present in the consultation.

### *Baseline and Outcome Measures*

Baseline assessments included patient demographic data, age, gender, education, race/ethnicity, print health literacy, health numeracy, state anxiety, and primary language. The post-consultation patient survey included measures of the patient centeredness of communication and decisional conflict as described below. Print health literacy was assessed with the Test of Functional Health Literacy in Adults,<sup>18,19</sup> and state anxiety was assessed with the State Trait Anxiety Inventory using validated

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Spanish and English forms of the measures.<sup>20</sup> All patient survey forms were administered in the participant's primary language.

### *Measurement of Health Numeracy*

Numeracy was assessed directly prior to the consultation using a Web-based program with the CAT-NUMi. The CAT-NUMi was developed using item response theory based on a theoretical framework of health numeracy that captured the domains of number sense, tables and graphs, probability, and statistics.<sup>4</sup> The computer adaptive form uses an algorithm to determine which items to administer to respondents based on responses they provide to the initial items. Using this approach, the CAT-NUMi is able to reach a precise measure of health numeracy while minimizing the response burden. The items are multiple choice with some including pictures or graphs to assess numeracy skills. The CAT-NUMi administered up to 10 questions to each patient and determined scores that ranged from  $-0.30$  to  $0.30$ , with higher values representing higher levels of numeracy.<sup>4,17</sup> The numeracy scores were categorized as low, medium, or high reflecting the distribution of scores in validation studies.<sup>16</sup>

### *Interpersonal Processes of Care*

The Interpersonal Processes of Care Measure (IPC) was used to assess patient-centered care and communication in the breast cancer consultation from the patient perspective. The short-form IPC-18 consists of 18 questions in six domains: Each domain results in a score from 1 to 5 with increasing values indicating a greater degree of the construct. The seven domains are lack of clarity, elicited concerns, explained results, compassionate, respectful, discrimination due to race/ethnicity, and disrespectful office staff.<sup>21</sup> For the domains lack of clarity, discrimination due to race/ethnicity, and disrespectful office staff, lower scores indicate higher quality communication. For the remaining domains, higher scores indicated high quality communication.

### *Decisional Conflict Scale*

The Decisional Conflict Scale (DCS) was used to assess post-consultation decisional conflict overall and in five subdomains: support, uncertainty, value clarity, effective decision, and informed.<sup>22</sup> The DCS has also been validated in a Spanish version.<sup>23</sup> Scores range from 0 to 100 with increasing scores indicating greater decisional

conflict. Scores lower than 25 are associated with implementing decisions and scores exceeding 37.5 are associated with decision delay.<sup>24</sup>

### *The OPTION Scale*

The 12-item OPTION (Observing Patient Involvement in Decision Making) scale was used to assess clinician behaviors of SDM in the cancer consultations. The OPTION scale measures clinician behavior, has strong content validity and acceptable measurement reliability for use in research settings, and has been widely used in studies of SDM.<sup>25-27</sup> Audio-recordings were translated (Spanish recordings) and transcribed verbatim. The two coders (AF and MS) reviewed and discussed coding on an initial set of five transcripts and then proceeded to code all transcripts independently. The final OPTION scores were determined by the mean scores of the two coders.<sup>28</sup> Each item was rated on a scale of 0 to 4 with the following interpretations: 0, the behavior is not attempted or observed; 1, minimal attempt at behavior; 2, behavior demonstrated at baseline skill level; 3, done to a good standard; and 4, exhibited to a high standard.<sup>29</sup> Summary scores are transformed to a scale of 0 to 100, with higher scores indicated increased skill in SDM.

### *Statistical Analysis*

Baseline demographic characteristics, clinical factors, and the distribution of cancer care providers (medical, radiation, or surgical oncologists) were compared between Spanish- and English-speaking using a Fisher's exact test or Wilcoxon rank-sum test for categorical or continuous outcomes, respectively. A multivariate linear regression with robust standard errors was used as a semiparametric approach to compare outcomes between groups while controlling for the patient and clinician factors found to differ between Spanish- and English-speaking groups in the bivariate analysis.<sup>30</sup> Provider specialty was included in the multivariate analysis for the OPTION scale as it was theoretically posited to be associated with behaviors of SDM. Clinic site and race/ethnicity were not included in the multivariate analyses due to collinearity as 100% of Spanish-speaking patients were from the Chicago site and of Hispanic ethnicity. A subset bivariate and multivariate analysis was conducted limited to patients from the Chicago site ( $n = 35$ ) to evaluate the robustness of findings within a common clinical site.

**Table 1** Baseline Characteristics of Study Population by Primary Language<sup>a</sup>

Participant Characteristics	Total Study Population ( <i>N</i> = 50), <i>n</i> (%)	Primary Language		<i>P</i> Value
		English ( <i>n</i> = 35), <i>n</i> (%)	Spanish ( <i>n</i> = 15), <i>n</i> (%)	
Study site				
Chicago	34 (32)	19 (55.9)	15 (100)	0.001
Milwaukee	16 (68)	16 (45)	0	
Education				
Up to high school/GED	17 (34)	10 (28.6)	7 (46.7)	0.470
Some college	17 (34)	12 (34.3)	5 (33.3)	
College degree	16 (32)	13 (37.1)	3 (20)	
Age, year, median (IQR) <sup>b</sup>	51 (46-61)	54 (49-62)	47 (40-54)	0.024
Race/ethnicity				
Non-Hispanic white	12 (24)	12 (34.3)	0	<0.0001
Non-Hispanic black	21 (42)	21 (60)	0	
Hispanic	17 (34)	2 (5.7)	15 (100)	
Numeracy level				
Low	18 (36.0)	11 (31.4)	7 (46.7)	0.392
Medium	18 (36.0)	12 (34.3)	6 (40)	
High	14 (28.0)	12 (34.3)	2 (13.3)	
CAT-NUMi Score, median (IQR) <sup>b</sup>	−0.2 (−0.82 to 0.81)	0.27 (−0.8 to 0.89)	−0.70 (−1.39 to −0.2)	0.011
TOFHLA scores, median (IQR) <sup>b</sup>	35.0 (33-35)	35.0 (33-36)	34.0 (32-35)	0.603
State Anxiety—STAI, median (IQR) <sup>b</sup>	41 (34-46)	41 (34-46)	41 (29-48)	0.664
Clinical specialty in oncology consultations				
Medical	13 (26)	10 (28.6)	3 (20)	0.857
Radiation	16 (32)	11 (31.4)	5 (33.3)	
Surgical	21 (42)	14 (40)	7 (46.7)	
Audio-recorded consultations	<i>n</i> = 46	<i>n</i> = 32	<i>n</i> = 14	—
Clinician specialty in audio-recorded oncology consultations				
Medical	11 (23.9)	9 (28.1)	2 (14.3)	0.656
Radiation	14 (30.4)	9 (28.1)	5 (35.7)	
Surgical	21 (46)	14 (43.8)	7 (50.0)	

CAT-NUMi Computer Adaptive Test -Numeracy Understanding in Medicine Instrument; GED, General Educational Development (high school-equivalency diploma); IQR, interquartile range; STAI, State-Trait Anxiety Inventory; TOFHLA, Test of Functional Health Literacy in Adults.<sup>18</sup>

<sup>a</sup>*P* value for Fisher's exact test reported, unless otherwise noted.

<sup>b</sup>Wilcoxon rank-sum test for age, CAT-NUMi score, TOFHLA, and STAI

## Results

### Study Population

Fifteen Spanish-speaking and 35 English-speaking patients participated in the study. Fifty-three percent (53%) of Spanish-speaking participants had a high school degree or a GED certificate as their highest level of education compared to 29% of English-speaking participants. Spanish-speaking participants were younger than English-speaking participants (median years, interquartile range [IQR]): 47, 40-54 versus 54, 49-62, *P* = 0.024, and had lower health numeracy scores (median, IQR): −0.70, −1.39 to −0.2 versus 0.27, −0.8 to 0.89, *P* = 0.011. There were no differences by language group in baseline print literacy or state anxiety scores (Table 1). All Spanish-speaking participants (100%) were all enrolled at the Chicago site. Of the 50

participants, 46 (32 English and 14 Spanish) were audio-recorded. One Spanish-speaking patient chose to have the consultation in English with the remainder using a professional translator.

### Distribution of Clinician Specialty in Breast Cancer Treatment Consultations

Of the 50 consultations, 42% (*n* = 21) were with a surgical oncologist, 32% (*n* = 16) with a radiation oncologist, and 26% (*n* = 11) with a medical oncologist. There was no statistically significant difference in the distribution of medical, radiation, or surgical oncologists between Spanish- and English-speaking participants overall or in the subset that were audio-recorded (Table 1).

**Table 2** Communication and Shared Decision Making Outcomes by Primary Language

Measure	Primary Language						P Value*
	Total Study Population, N = 50		English, n = 35		Spanish, n = 15		
	n	Median (IQR)	n	Median (IQR)	n	Median (IQR)	
Decisional Conflict Scale total	48	18.0 (6.3-25.8)	33	18.8 (6.3-26.6)	15	15.6 (1.6-23.4)	0.713
Support	49	16.7(0-25)	34	16.7 (0-25)	15	8.3 (8.3-25)	0.522
Uncertainty	49	16.7 (8.3-25)	34	20.8 (8.3-41.7)	15	16.7 (8.3-25)	0.409
Effective	48	18.8 (0-25)	33	18.8 (0-25)	15	18.8 (0-18.8)	0.420
Values clarity	49	16.7 (8.3-25)	34	16.7 (8.3-25)	15	16.7 (0-25)	0.947
Informed	49	16.7 (8.3-25)	34	16.7 (8.3-25)	15	25 (8.3-33.3)	0.436
Interpersonal Processes of Care Scale							
Lack of clarity	49	1.5 (1-2)	34	1.5 (1-2)	15	2.5 (1-3)	0.028
Elicited concerns	50	4.8(4.7-5)	35	5 (4.3-5)	15	4.7 (4.7-5)	0.954
Explained results	50	5 (4-5)	35	5 (5-5)	15	5 (4-5)	0.369
Patient-centered decision making	47	5 (3.5-5)	33	5 (3.5-5)	14	3 (4.5-5)	0.565
Compassionate, respectful	49	5 (4.7-5)	34	5 (4.7-5)	15	5 (4.7-5)	0.884
Discrimination	49	1 (1-1)	34	1 (1-1)	15	1 (1-1)	0.047
Disrespectful office staff	49	1 (1-1)	34	1 (1-1)	15	1.3 (1-2)	0.0005
OPTION scale total score	46	27.6 (20.8-35.4)	32	31.3 (24.0-37.5)	14	22.9 (17.7-28.1)	0.0204

IQR, interquartile range; OPTION, Observing Patient Involvement in Decision Making scale.

\*P value for Wilcoxon rank-sum test.

### Patient-Reported Measures

Evaluation of patient-centered care and communication as measured by the IPC indicated lower patient centeredness (median, IQR) in domains of *lack of clarity*: 2.5, 1-3 versus 1.5, 1-2,  $P = 0.028$ ; *perceived discrimination due to race or ethnicity*: 1, 1-1 versus 1.1, 1-1,  $P = 0.047$ ; and *disrespectful office staff*: 1.25, 1-2 versus 1, 1-1,  $P = 0.0005$  (Table 2). No statistically significant differences were found in the DCS total scores between Spanish- and English-speaking participants (median, IQR): 15.65, 1.56-23.44 versus 18.75, 6.25-26.56,  $P = 0.713$ , respectively, or between the DCS subdomains (Table 2).

In multivariate analyses controlling for age and health numeracy, the IPC domain scores of *lack of clarity* and *disrespectful office staff* remained statistically significantly higher (indicating less patient-centered care) in Spanish- versus English-speaking participants (mean difference, 95% confidence interval [CI], P value): 0.554, 0.047 to 1.06,  $P = 0.033$ , and 0.515, 0.101 to 0.929,  $P = 0.016$ , respectively (Tables 3 and 4).

### OPTION Scale Results

Among the 46 consultations that were audio-recorded, the OPTION score (median, IQR) was 27.6, 20.8 to 36.4. The OPTION scores were lower in Spanish- versus English-speaking participants (median, IQR): 21.9, 17.7 to 27.1 versus 31.3, 26.6 to 39.6,  $P = 0.0014$ , respectively.

**Table 3** Linear Regression With Robust Standard Error Predicting Lack of Clarity on the Interpersonal Processes of Care Scale

	Mean Difference (95% CI)	P Value
Spanish language	0.553 (0.046, 1.06)	0.033
Age, years	-0.010 (-0.028, 0.008)	0.269
Numeracy score	0.011 (-0.139, 0.162)	0.880

CI, confidence interval.

**Table 4** Linear Regression With Robust Standard Error Predicting Disrespectful Office Staff on the Interpersonal Processes of Care Scale

	Mean Difference (95% CI)	P Value
Spanish language	0.516 (0.101, 0.931)	0.016
Age, years	-0.007 (-0.022, 0.009)	0.403
Numeracy score	-0.0007 (-0.117, 0.11)	0.990

CI, confidence interval.

The highest scoring items were the following: Item 1—The clinician draws attention to an identified problem as one that requires a decision making process; Item 2—The

**Table 5** Option Scores by Item and Total Score by Primary Language for Audio-Recorded Consultations

OPTION Item	Total (N = 46), Median (IQR)	Primary Language	
		English (n = 32), Median (IQR)	Spanish (n = 14), Median (IQR)
1. The clinician draws attention to an identified problem as one that requires a decision making process.	4.2 (3.1-4.2)	4.2 (3.1-4.7)	3.1 (3.1 to -4.2)
2. The clinician states that there is more than one way to deal with the identified problem (“equipoise”).	4.2 (2.1-5.2)	4.2 (2.6-5.2)	4.2 (2.1-4.2)
3. The clinician assesses the patient’s preferred approach to receiving information to assist decision making (e.g., discussion, reading printed material, assessing graphical data, using videotapes or other media).	0 (0-1.0)	0 (0-1.0)	0 (0-0)
4. The clinician lists “options,” which can include the choice of “no action.”	3.1 (2.1-4.2)	3.1 (2.1-4.2)	2.1 (1.0-3.1)
5. The clinician explains the pros and cons of options to the patient (taking “no action” is an option).	3.1 (2.1-4.2)	3.6 (2.1-4.7)	3.1 (2.1-4.2)
6. The clinician explores the patient’s expectations (or ideas) about how the problem(s) are to be managed.	1.0 (0-2.1)	2.1(1.0-2.1)	1.0 (0-1.0)
7. The clinician explores the patient’s concerns (fears) about how problem(s) are to be managed.	2.1 (1.0-3.1)	3.1 (2.1-4.2)	1.6 (1.0-2.1)
8. The clinician checks that the patient has understood the information.	3.1 (1.0-4.2)	3.1 (1.6-3.6)	1.0 (1.0-5.2)
9. The clinician offers the patient explicit opportunities to ask questions during the decision making process.	4.2 (3.1-4.2)	4.2 (3.1-4.2)	4.2 (2.1-4.2)
10. The clinician elicits the patient’s preferred level of involvement in decision making.	0 (0-0)	0 (0-0)	0(0-0)
11. The clinician indicates the need for a decision making (or deferring) stage.	2.1 (1.0-3.1)	2.1 (1.0-3.1)	1.0 (0-2.1)
12. The clinician indicates the need to review the decision (or deferment).	2.6 (0-4.2)	3.1 (1.6-4.2)	1.6 (0-3.1)
Total score	27.6 (20.8-35.4)	31.3 (24.0-37.5)	22.9 (17.7-28.1)

IQR, interquartile range; OPTION, Observing Patient Involvement in Decision Making scale.

clinician states that there is more than one way to deal with the identified problem (“equipoise”); and Item 9—The clinician offers the patient explicit opportunities to ask questions during the decision-making process. The lowest scoring items were the following: Item 3—The clinician assesses the patient’s preferred approach to receiving information to assist decision making (e.g., discussion, reading printed material, assessing graphical data, using videotapes or other media); and Item 10—The clinician elicits the patient’s preferred level of involvement in decision making, with median scores reflecting that the behavior was not observed at all (Table 5).

In multivariate analyses controlling for baseline age, health numeracy, and clinician specialty, there were no statistically significant differences in total OPTION scores between language groups (mean difference:  $-2.51$ , 95% CI:  $-7.37$  to  $2.36$ ,  $P = 0.304$ ). Increased patient health numeracy remained associated with higher OPTION scores (Table 6).

### Results of Subset Analysis

Within the Chicago site, there was no statistically significant difference between groups in years of age (median, IQR): 48, 40 to 56 versus 51, 47 to 59,  $P = 0.212$ ; education level (%): high school graduate or GED: 47% versus 28%, some college: 33% versus 33%, college degree 20% versus 37%,  $P = 0.805$ ; or health numeracy score (median, IQR):  $-0.82$ ,  $-1.39$  to  $-0.2$  versus  $-0.6$ ,  $-0.86$  to  $-0.16$ ,  $P = 0.267$ , for Spanish- versus English-speaking patients, respectively. In bivariate analysis, IPC scores were higher in Spanish- versus English-speaking patients in the domains of *lack of clarity* (median, IQR): 2.5, 1-3 versus 1.5, 1-1.5,  $P = 0.024$ , and *disrespectful office staff* (median, IQR): 1.25, 1-2 versus 1, 1-1,  $P = 0.016$ , respectively. These findings persisted in multivariate analyses after controlling for patient age and health numeracy (mean difference, 95% CI,  $P$  value) for IPC domains of *lack of clarity* (0.545, 0.024 to 1.064,  $P = 0.041$ ) and

**Table 6** Linear Regression With Robust Standard Error Predicting Shared Decision Making OPTION Scores

	Mean Difference (95% CI)	P Value
Spanish language	-2.57 (-7.563 to 2.426)	0.305
Age, years	0.160 (-0.054 to 0.375)	0.139
Numeracy score	4.561 (2.078 to 7.043)	<0.001
Provider specialty <sup>a</sup>		
Surgical oncology	2.231 (-3.292 to 7.755)	0.419
Medical oncology	-3.667 (-8.891 to 1.157)	0.128
Radiation oncology	—	—

CI, confidence interval; OPTION, Observing Patient Involvement in Decision Making scale.

<sup>a</sup>Surgical, medical, and radiation oncology entered as dummy variables in analysis.

*disrespectful office staff* (0.466, 0.075 to 0.857,  $P = 0.021$ ). In multivariate analysis, increased patient health numeracy was associated with higher OPTION scores (mean difference: 4.561, 95% CI: 2.078 to 7.043,  $P = 0.001$ ) and a consultation with a medical versus surgical oncologist was associated with lower OPTION scores (mean difference: -6.096, 95% CI: 11.329 to -0.867,  $P = 0.023$ ).

## Discussion

In this study, we evaluated the patient centeredness of care and clinician behaviors of SDM in the treatment consultation among cohort of Spanish- and English-speaking patients with a new diagnosis of stage 0 to 3 breast cancer. We considered multilevel factors including patient age, education, health print literacy and health numeracy, provider specialty, and study site. Our findings indicate differences in patient centeredness of care in the domains of *lack of clarity* and *disrespectful office staff*, with Spanish-speaking patients reporting lower levels of patient-centered care. Both Spanish- and English-speaking patients had low levels of post-consultation decisional conflict with median scores on the DCS of 18.0.<sup>24</sup> We report no statistically significant difference in OPTION scores between Spanish- and English-speaking patients after controlling for patient-level factors and clinician specialty.

Our study is consistent with the literature in noting cross-cultural differences in the quality of communication in medical care settings. Previous studies have reported higher levels of perceived disrespect among Hispanic patients compared to other racial/ethnic groups.<sup>12,15,31</sup> A study of communication and quality of

life among breast cancer survivors by Kwan et al. found Hispanic versus non-Hispanic white women to perceive lower patient centeredness of communication in the IPC domains of lack of clarity and discrimination due to race/ethnicity.<sup>12</sup> In contrast to the current study, the Kwan study<sup>12</sup> did not compare the experiences of English- and Spanish-speaking patients nor evaluate the communication that occurred in the initial cancer treatment consultation. In a study that used data from the Commonwealth Fund 2001 Health Care Quality Survey, persons of Hispanic ethnicity were more likely than those who were non-Hispanic white or black to perceive disrespect in the patient-provider relationship.<sup>31</sup> Finally, in a longitudinal cohort study of the menopausal transition conducted at seven US sites, Jacobs et al. reported higher perceived racial discrimination between Hispanic and non-Hispanic white women (12% v. 3%).<sup>15</sup>

Our findings add to previous literature in reporting perceived racism among Hispanic and Latino patients. In a 2003 California Health Interview Survey on cancer risk behaviors, Latino patients reported higher rates of perceived racism in health care compared to non-Hispanic white, African American or black, Pacific Islander, and American Indian or Alaska Native patients. Self-reported experience with racism in health care was associated with not being up to date with cancer screening tests.<sup>32</sup>

In addition to barriers attributed to ethnicity, language may pose a barrier to patient-centered communication.<sup>33,34</sup> Jacobs et al. reported that the provision of interpreter services can mitigate disparities in health outcomes associated with limited English proficiency.<sup>8</sup>

Our study is the first prospective study we are aware of to compare the quality of communication and SDM between English- and Spanish-speaking patients. The findings suggest that despite having interpreters present, disparities persist in patient centeredness of communication. Although cross-cultural studies of decisional conflict are limited, one study among parents of children with a life threatening illness found that persons who were non-Latino white versus Latino reported higher scores in the DCS domains of effective decision making and support in decision-making.<sup>35</sup>

The quality of patient-centered communication has implications for patient health and psychosocial outcomes including quality of life, adherence to cancer screening guidelines, and satisfaction.<sup>12,13,36,37</sup> Lower levels of patient-centered communication as indicated by the lack of clarity, perceived discrimination, and disrespectful office staff domains on the IPC were associated with lower quality of life in a cohort of breast cancer

survivors.<sup>12</sup> Higher perceived discrimination among Hispanic/Latino men has been associated with lower adherence to cancer screening guidelines.<sup>13</sup> In a study among an ethnic and racially diverse group of adults aged 50 and older, the perceived interpersonal sensitivity of the provider seen most recently in the past year was positively associated with satisfaction with health care.<sup>36</sup> A study of the association of patient perceptions of communication by health care providers with patient language (English v. Spanish) and ethnicity (Latino v. white) found that Spanish-speaking and Latino patients were less satisfied than English-speaking and white patients with how well medical staff listened, answered their questions, explained medications, explained medical procedures and tests results, and provided reassurance and support.<sup>38</sup> Finally, a survey of 1600 persons in a general medicine practice reports that lack of clarity and perceived disrespectful office staff as measured by the IPC were associated with lower satisfaction among Spanish-speaking patients with the association of disrespectful office staff and satisfaction noted in all race and ethnic groups.<sup>37</sup>

Communication in the cancer setting is a particularly important concern as complex information is conveyed regarding diagnosis, severity of disease, treatment, and expected outcomes.<sup>39</sup> Quantitative information may convey these concepts.<sup>4-6,40</sup> A study using data from the 2007 National Cancer Institute's HINTS reported lower levels of confidence in the use of numeric information among black and Hispanic compared to white groups.<sup>41</sup>

The OPTION scores we report indicate a basic level of SDM skill with a median score in the total cohort of 27.6 (IQR 20.8-35.4), on a scale of 0 to 100. Our findings are consistent with a number of previous studies. A systematic review of 14 studies across clinical settings (not including a SDM intervention) reported an OPTION score with a mean (SD) of 23 (14).<sup>26</sup> A study of consultations with medical, radiation, or surgical oncologists in Australia and New Zealand among 55 patients with breast cancer reported OPTION scores with a mean (SD) of 23.4 (9.2).<sup>42</sup> A multicenter cross-sectional study of SDM among 114 consultations with primary care physicians based in Quebec, Canada, reported OPTION scores with a median (range) of 25.0 (6-25).<sup>43</sup> In contrast, a study of radiation and medical oncology consults among 55 patients with colorectal or breast cancer in the Netherlands reported lower OPTION scores with a median (range) of 10 (2-60).<sup>44</sup>

Previous studies have identified provider and patient factors associated with clinician SDM behaviors as measured by the OPTION scale. A systematic review identified 1) use of an intervention to implement SDM

and 2) consultations longer in duration, as factors associated with higher OPTION scores.<sup>26</sup> In a multicenter, cross-sectional study of primary care physicians, factors associated with higher OPTION scores included the following: 1) physician participation on work-related committees, 2) consultations longer in duration, 3) increased decisional conflict in patients, and 4) patients that are employed.<sup>43</sup>

We report that higher patient health numeracy was associated with higher levels of clinician SDM behavior as measured by the OPTION scale. As part of the parent study design, participants in our study were tested for health numeracy directly prior to the consultation and results were shared with the clinician at the point of care. It is possible that clinicians adjusted their communication strategy to the patient's level of health numeracy. In an analysis of the parent study, 33% of clinicians stated they modified their communication approach a little or somewhat based on the patient health numeracy report. Clinicians were also more likely to use a percent format when discussing prognosis in consultations with more versus less numerate patients. However, no difference was found in the use of other numeric formats including whole numbers, proportions, decimals, or indications of statistical uncertainty.<sup>16</sup> Further studies are needed to understand the relationship between patient health numeracy and the quality of SDM in the cancer consultation.


Patients with early stage breast cancer may consult with clinicians across several oncology specialties in the process of making a treatment plan. The balance between providing information about cancer and cancer treatment versus focusing on the decision-making process may vary between medical, radiation, and surgical oncologists. Patients with early-stage breast cancer often face a decision of equipoise regarding mastectomy versus a combination of lumpectomy and radiation as initial treatment. This is a decision directly involving surgical and radiation oncologists. Other breast cancer treatment decisions that can approach equipoise include whether to use adjuvant or neoadjuvant chemotherapy, a decision most likely to be discussed by a medical oncologist. Given the varied clinical domains of the oncology providers in the study, we included clinician specialty in our multivariate analysis. There was no association of clinical specialty with OPTION scores in our primary analysis. However, in the subset analysis limited to the Chicago site, the specialty of medical oncology was associated with lower OPTION scores than surgical oncology. Larger studies are needed to further evaluate the differences in cancer communication and SDM across clinician specialties in cancer care.



Our study has several limitations. First, Spanish-speaking participants were younger and had lower levels of health numeracy than the English-speaking patients and were treated in only one of the two participating sites. However, we were able to control for patient-level factors in our analysis and conducted a sensitivity analysis within the Chicago site. Second, we did not track the number or evaluate the quality of interpreters and variation in interpreter services could influence the quality of communication. Third, our sample size limits the power to discern differences between groups. Finally, we used the OPTION scale to evaluate clinician behaviors of SDM. Although widely used, this scale has psychometric limitations including questions regarding its factorial structure, item independence, and correlation with other theoretically based measures of SDM.<sup>25</sup> Despite these limitations, our study had certain strengths. We measured decisional conflict and patient-centered communication in a prospective manner among participants at a similar stage in their disease course. The measures used to assess health numeracy, decisional conflict, and patient-centered communication have been validated for English- and Spanish-speaking respondents. Finally, we had audio-recordings of the consultations and were thus able to observe SDM behavior.

In conclusion, our findings highlight challenges in cancer communication for Spanish-speaking patients, particularly with respect to perceived patient centeredness of care. We report comparable provider skill in SDM between consultations conducted with Spanish- and English-speaking patients. Our SDM findings are consistent with others in suggesting that patient health numeracy may be an important challenge to address in future interventions. Further cross-cultural studies are needed to understand and address cultural and language barriers to effective communication and SDM in cancer care.

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## References

1. Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns*. 2006;62(3):355–60.
2. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns*. 2006;60(3):301–12.
3. Bowen DJ, Allen JD, Vu T, Johnson RE, Fryer-Edwards K, Hart A Jr. Theoretical foundations for interventions designed to promote informed decision making for cancer screening. *Ann Behav Med*. 2006;32(3):202–10.
4. Schapira MM, Walker CM, Cappaert KJ, et al. The numeracy understanding in medicine instrument: a measure of health numeracy developed using item response theory. *Med Decis Making*. 2012;32(6):851–65.
5. Golbeck AL, Ahlers-Schmidt CR, Paschal AM, Dismuke SE. A definition and operational framework for health numeracy. *Am J Prev Med*. 2005;29(4):375–6.
6. Ancker JS, Kaufman D. Rethinking health numeracy: a multidisciplinary literature review. *J Am Med Assoc*. 2007;14(6):713–21.
7. Jacobs EA, Walker CM, Miller T, et al. Development and validation of the Spanish Numeracy Understanding in Medicine Instrument. *J Gen Intern Med*. 2016;31(11):1345–52.
8. Jacobs EA, Shepard DS, Suaya JA, Stone EL. Overcoming language barriers in health care: costs and benefits of interpreter services. *Am J Public Health*. 2004;94(5):866–9.
9. Sepucha KR, Scholl I. Measuring shared decision making: a review of constructs, measures, and opportunities for cardiovascular care. *Circ Cardiovasc Qual Outcomes*. 2014;7(4):620–6.
10. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361–7.
11. Vogel BA, Leonhart R, Helmes AW. Communication matters: the impact of communication and participation in decision making on breast cancer patients' depression and quality of life. *Patient Educ Couns*. 2009;77(3):391–7.
12. Kwan ML, Tam EK, Ergas IJ, et al. Patient-physician interaction and quality of life in recently diagnosed breast cancer patients. *Breast Cancer Res Treat*. 2013;139(2):581–95.
13. Valdovinos C, Penedo FJ, Isasi CR, et al. Perceived discrimination and cancer screening behaviors in US Hispanics: the Hispanic Community Health Study/Study of Latinos Sociocultural Ancillary Study. *Cancer Causes Control*. 2016;27(1):27–37.
14. Vadaparampil ST, Quinn GP, Small BJ, et al. A pilot study of hereditary breast and ovarian knowledge among a multi-ethnic group of Hispanic women with a personal or family history of cancer. *Genet Test Mol Biomarkers*. 2010;14(1):99–106.
15. Jacobs EA, Rathouz PJ, Karavolos K, et al. Perceived discrimination is associated with reduced breast and cervical cancer screening: the Study of Women's Health Across the Nation (SWAN). *J Womens Health (Larchmt)*. 2014;23(2):138–45.
16. Schapira MM, Fletcher KE, Ganschow PS, et al. Improving communication in breast cancer treatment consultation: use of a computer test of health numeracy [published online June 25, 2019]. *J Womens Health*. doi:10.1089/jwh.2018.7347
17. Schapira MM. Development of a computer adaptive test of health and numeracy: the CAT-NUMi. Paper presented at: 5th Health Literacy Annual Research Conference (HARC); October 28–29, 2013; Washington.

18. Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med.* 1995;10(10):537–41.
19. Aguirre AC, Ebrahim N, Shea JA. Performance of the English and Spanish S-TOFHLA among publicly insured Medicaid and Medicare patients. *Patient Educ Couns.* 2005;56(3):332–9.
20. Spielberger CD. Manual for the state-trait anxiety inventory. STAI (form Y). Palo Alto, CA: Consulting Psychologists Press; 1983.
21. Stewart AL, Napoles-Springer AM, Gregorich SE, Santoyo-Olsson J. Interpersonal processes of care survey: patient-reported measures for diverse groups. *Health Serv Res.* 2007;42(3 Pt. 1):1235–56.
22. O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making.* 1995;15(1):25–30.
23. Urrutia M, Campos S, O'Connor A. Validation of a Spanish version of the Decisional Conflict Scale [in Spanish]. *Rev Med Chil.* 2008;136(11):1439–47.
24. O'Connor AM. User manual—Decisional Conflict Scale. Available from: [https://decisionaid.ohri.ca/docs/develop/User\\_Manuals/UM\\_Decisional\\_Conflict.pdf](https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf)
25. Nicolai J, Moshagen M, Eich W, Bieber C. The OPTION scale for the assessment of shared decision making (SDM): methodological issues. *Z Evid Fortbild Qual Gesundheitsw.* 2012;106(4):264–71.
26. Couet N, Desroches S, Robitaille H, et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expect.* 2015;18(4):542–61.
27. Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. *Qual Safety Health Care.* 2003;12(2):93–9.
28. Elwyn G. OPTION: Observing Patient Involvement Training Pack. Available from: [http://www.glynelwyn.com/uploads/2/4/0/4/24040341/option\\_12\\_training\\_pack.pdf](http://www.glynelwyn.com/uploads/2/4/0/4/24040341/option_12_training_pack.pdf).
29. Elwyn G, Hutchings H, Edwards A, et al. The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Health Expect.* 2005;8(1):34–42.
30. Long JS, Ervin LH. Using heteroscedasticity consistent standard errors in the linear regression model. *Am Stat.* 2000;54:217–24.
31. Blanchard J, Lurie N. R-E-S-P-E-C-T: patient reports of disrespect in the health care setting and its impact on care. *J Fam Pract.* 2004;53(9):721–30.
32. Shariff-Marco S, Klassen AC, Bowie JV. Racial/ethnic differences in self-reported racism and its association with cancer-related health behaviors. *Am J Public Health.* 2010;100(2):364–74.
33. Hull M. Medical language proficiency: a discussion of interprofessional language competencies and potential for patient risk. *Int J Nurs Stud.* 2016;54:158–72.
34. Schwei RJ, Del Pozo S, Agger-Gupta N, et al. Changes in research on language barriers in health care since 2003: a cross-sectional review study. *Int J Nurs Stud.* 2016;54:36–44.
35. Knapp C, Sberna-Hinojosa M, Baron-Lee J, Curtis C, Huang IC. Does decisional conflict differ across race and ethnicity groups? A study of parents whose children have a life-threatening illness. *J Palliat Med.* 2014;17(5):559–67.
36. Phillips KL, Chiriboga DA, Jang Y. Satisfaction with care: the role of patient-provider racial/ethnic concordance and interpersonal sensitivity. *J Aging Health.* 2012;24(7):1079–90.
37. Napoles AM, Gregorich SE, Santoyo-Olsson J, O'Brien H, Stewart AL. Interpersonal processes of care and patient satisfaction: do associations differ by race, ethnicity, and language? *Health Serv Res.* 2009;44(4):1326–44.
38. Morales LS, Cunningham WE, Brown JA, Liu H, Hays RD. Are Latinos less satisfied with communication by health care providers? *J Gen Intern Med.* 1999;14(7):409–17.
39. Stajduhar KI, Thorne SE, McGuinness L, Kim-Sing C. Patient perceptions of helpful communication in the context of advanced cancer. *J Clin Nurs.* 2010;19(13-14):2039–47.
40. Schapira MM, Fletcher KE, Ganschow PS, et al. The meaning of numbers in health: exploring health numeracy in a Mexican-American population. *J Gen Intern Med.* 2011;26(7):705–11.
41. Huang H, Chan YM, Feng D. Health numeracy confidence among racial/ethnic minorities in HINTS 2007: sociodemographic, attitudinal, and knowledge correlates. *Literacy Numeracy Stud.* 2012;20(2):3–16.
42. Butow P, Juraskova I, Chang S, Lopez AL, Brown R, Bernhard J. Shared decision making coding systems: how do they compare in the oncology context? *Patient Educ Couns.* 2010;78(2):261–8.
43. Menear M, Garvelink MM, Adekpedjou R, et al. Factors associated with shared decision making among primary care physicians: findings from a multicentre cross-sectional study. *Health Expect.* 2018;21(1):212–21.
44. Kunneman M, Engelhardt EG, Hove FLT, et al. Deciding about (neo-)adjuvant rectal and breast cancer treatment: missed opportunities for shared decision making. *Acta Oncol.* 2016;55(2):134–9.