

Decision Involvement and Receipt of Mastectomy Among Racially and Ethnically Diverse Breast Cancer Patients

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- Background** Few studies have evaluated the association between patient decision involvement and surgery received among racially and ethnically diverse patients or patients' attitudes about surgery and the role of family and friends in surgical treatment choices.
- Methods** Women diagnosed with nonmetastatic breast cancer from June 2005 through February 2007 and reported to the Los Angeles or Detroit Surveillance, Epidemiology, and End Results registries were mailed a survey after diagnosis (N = 3133). Latina and African American women were oversampled. The response rate was 72.4%. The analytic sample (N = 1651) excluded those with stage IIIA or higher disease, self-reported clinical contraindications to breast-conserving surgery with radiation, and unclear race or ethnicity. The dependent variable was receipt of mastectomy initially. The primary independent variables were patient involvement in decision making, race or ethnicity, attitudes about recurrence, the effects of radiation, the impact of surgery on body image, and the role of others in decision making. Latinas were categorized as low or high acculturated. The association between patient involvement in decision making and the receipt of mastectomy was evaluated using logistic regression while controlling for other independent variables. All statistical tests were two-sided.
- Results** The analytic sample was 23.9% Latina (12.0% low acculturated, 11.9% high acculturated), 27.1% African American, and 48.9% white, and 17.2% received a mastectomy initially. For each racial or ethnic group, more women who reported a patient-based decision received mastectomy than those who reported a shared or surgeon-based decision ($P = .022$ for low-acculatuated Latinas, $P < .001$ for other groups). Women who reported that concerns about recurrence or radiation effects were very important in their surgery decision were more likely to receive mastectomy than those less concerned (for recurrence concerns, estimated relative risk [RR] = 1.66, 95% confidence interval [CI] = 1.28 to 2.10; for radiation concerns, estimated RR = 2.35, 95% CI = 1.88 to 2.85). Women who reported that body image concerns and their spouse's opinion were very important in their surgery decision less often received mastectomy than those less concerned about body image or who placed less weight on their spouse's opinion (for body image concerns, estimated RR = 0.47, 95% CI = 0.30 to 0.74; for spouse's opinion, estimated RR = 0.53, 95% CI = 0.36 to 0.78).
- Conclusion** Greater patient involvement in decision making was associated with receipt of mastectomy for all racial and ethnic groups. Patient attitudes about surgery and the opinions of family and friends contribute to surgical choices made by women with breast cancer.

J Natl Cancer Inst 2009;101:1337-1347

Concerns about the excessive use of mastectomy for women who are newly diagnosed with breast cancer have lingered for more than a decade. Summary results from randomized controlled trials of surgical treatment options for breast cancer that included a large number of patients observed for up to 20 years have shown that mastectomy and breast-conserving surgery with radiation confer equivalent survival and nearly equivalent local recurrence outcomes (1-4). These results have motivated many professional organizations to endorse breast-conserving surgery with radiation

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See "Funding" and "Notes" following "References."

DOI: 10.1093/jnci/djp271

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Advance Access publication on August 31, 2009.

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CONTEXT AND CAVEATS

Prior knowledge

Although variation in patient involvement in breast cancer surgical treatment decisions exists, few studies have evaluated the association between patient decision involvement and receipt of surgery among racially and ethnically diverse patients or patients' attitudes about surgery and the role of family and friends in surgical treatment choices.

Study design

Women diagnosed with nonmetastatic breast cancer from June 1, 2005, through February 1, 2007, who were reported to the Surveillance, Epidemiology, and End Results registries in the Los Angeles and Detroit metropolitan areas were mailed a survey soon after diagnosis to ascertain the degree of patient involvement in decision making, race or ethnicity, attitudes about disease recurrence, the effects of radiation, and the impact of surgery on body image and the role of friends and family in decision making. Latina and African American women were oversampled.

Contribution

Greater patient involvement in decision making was associated with greater receipt of mastectomy in all racial and ethnic groups. Women who reported that concerns about recurrence or the effects of radiation were very important in their treatment decision making were more likely to receive mastectomy initially than those who were less concerned, whereas those who reported that concern about body image and their spouse's opinion were very important factors in their surgery decision were less likely to receive mastectomy initially than those who were less concerned or placed less weight on their spouse's opinion.

Implications

Patient attitudes about surgery as well as the opinions of family and friends contribute to surgical choices made by women with breast cancer.

Limitations

Patient involvement was self-assessed and may be subject to recall bias. The results may not be generalizable to all women with breast cancer. Some measures, such as decision involvement and patient attitudes, have not been validated in Spanish-speaking populations.

From the Editors

as the preferred treatment for eligible patients with early-stage breast cancer. Indeed, the use of breast-conserving surgery with radiation has emerged as a quality indicator that is promoted by some health-care systems (5–7).

Data from population-based cancer registries as well as from clinical settings indicate that the current rate of mastectomy for early-stage breast cancer ranges from 20% to 40% (8–10). Mastectomy rates also vary markedly across geographic areas in the United States (11,12). In addition, receipt of mastectomy is associated with clinical characteristics, including tumor size and tumor behavior (12–14), and possibly with demographic factors, including the patient's race, ethnicity, education level, and income.

The receipt of surgery for breast cancer is determined by the interplay between the surgeon's recommendation and the patient's preferences. Some have argued that the variation in mastectomy rates may be explained, in part, by a lack of patient involvement in

decisions about surgery for breast cancer (15–17), particularly among racial and ethnic minorities and socioeconomically disadvantaged groups (18). Although there has been much research describing the role of patients in decision making about surgical treatment for breast cancer (19–24), relatively little has linked patient involvement in treatment decisions to actual treatment utilization, and the results of this research are mixed. Two studies found that greater patient involvement in treatment decision making is associated with more frequent receipt of mastectomy (25,26); however, another study did not corroborate this finding (27). A patient's concerns about breast cancer recurrence have been associated with the receipt of mastectomy (25). A recent study showed that other patient attitudes, such as the desire to keep the breast and to avoid undergoing radiation therapy, were also associated with the choice of mastectomy (28).

The studies to date regarding patient decision making and surgical choice have several limitations that need to be considered. First, they failed to distinguish between mastectomy as the initial surgical treatment for the affected breast vs mastectomy after initial breast-conserving surgery with radiation. Importantly, some research suggests that approximately 9% of patients who received mastectomy underwent the procedure after unsuccessful initial attempts at breast-conserving surgery (M. Morrow, R. Jagsi, A. A. Alderman, unpublished data). The decision-making process is likely to be quite different for initial surgical treatment and re-excision after initial breast-conserving surgery with radiation. Second, the studies to date have been limited in the diversity of the patient population, and none has had large numbers of racial or ethnic minorities, particularly Latina patients. Latinas constitute a growing proportion of the US population and are increasingly represented among women who are diagnosed with breast cancer (29); yet, few published reports have addressed the perspectives of Latinas regarding breast cancer treatment decision making. Two studies found that despite the similar rates of surgical procedures among Latina women and women of other racial and ethnic groups, less acculturated Latina women reported much greater dissatisfaction with the decision process than other women (30) and expressed a desire for more information (31). Some studies suggest that language, literacy, and acculturation may pose barriers to informed treatment decision making, particularly for Latina breast cancer patients (32–34). Patients of Latina ethnicity have also been found to involve others in treatment decision making more often than non-Latina breast cancer patients (32–34). However, these studies were limited by their small sample sizes and selected clinical settings. Finally, no studies to our knowledge have evaluated the degree to which patients' families and friends contribute to treatment decision making and treatment choices, despite research showing the importance of family and friends to Latina patients in particular (32).

To address these gaps in our knowledge about breast cancer treatment decision making, we performed a population-based study in two large US urban areas with two research objectives: 1) to evaluate the association between patient involvement in decision making and the receipt of mastectomy among racially and ethnically diverse patients with early-stage breast cancer and 2) to assess factors associated with choice of mastectomy as the initial treatment for breast cancer, including patient attitudes regarding surgery and the involvement of others in the decision-making process.

On the basis of previous work (25), we hypothesized that, overall, more patient involvement in decision making would be associated with receipt of mastectomy and that patient attitudes would be associated with the decision whether or not to have mastectomy.

Methods

Study Population and Sampling

The eligible study population consisted of women aged 20–79 years at diagnosis with an incident case of primary ductal carcinoma in situ (stage 0) or invasive breast cancer (stage I–IIIb), based on the Surveillance, Epidemiology, and End Results (SEER) summary stage (35). Any such patients who were white, African American, or Latina and were reported to the Los Angeles Cancer Surveillance Program or the Metropolitan Detroit Cancer Surveillance System, the SEER program registries for the metropolitan areas of Los Angeles, California, and Detroit, Michigan, respectively, from June 1, 2005, through February 1, 2007, were eligible. Asian women were excluded because they were being recruited for another Los Angeles SEER study, and SEER protocol generally prohibits enrollment into multiple concurrent studies. SEER registries are population based, meaning that patient information is obtained by the registry from all sources in the SEER catchment area (36). Using a population-based registry yields a study sample that is generally representative of the population of the respective geographic area in terms of sex, race or ethnicity, age, and other demographic characteristics (36). We used the rapid case ascertainment method (37), which allows the SEER registries to identify patients within 1 month of their diagnosis. From the Los Angeles sample, we selected all African American women based on demographic information provided by the treating hospitals to the SEER registry. Because Latina status is not always accurately collected by the treating hospital at the time of diagnosis, we used an alternative sampling strategy to identify the maximum number of Latina patients among the Los Angeles sample. We selected all women who were designated as Hispanic by their treating hospital and all women whose surname indicated a high probability that they were Latina based on a list of Spanish surnames generated from the 1980 US Census (38). We then selected a random sample of approximately 11% of the white (non-Spanish-surnamed) patients. From the Detroit sample, we likewise selected all African American women based on the demographic information provided by the hospitals in which they were treated. We then selected a random sample of approximately 67% of the remaining non-African American patients, whom we classified as white.

Data Collection

We notified the physician of each selected patient of our intention to contact his or her patient and gave the physician the option to exclude any patient(s). If there was no physician objection, we initiated the Dillman method (39) for contacting patients to encourage a survey response from those patients who were identified as eligible based on the criteria above. This method involves mailing an introductory letter, survey materials, including an informed consent form describing the risks and benefits of participation, a self-addressed stamped return envelope, and a monetary incentive (\$10) (39). A multimethod follow-up approach was used, including

a postcard reminder sent within 3 weeks of nonresponse followed by a telephone reminder by a bilingual SEER staff member (39). Participants were encouraged to complete the survey from the original packet; some were sent a second survey if necessary. A telephone option was offered to those for whom reminders did not result in return of a completed survey.

The patient survey instrument (available online as Supplementary material) was translated into Spanish using a standard approach that includes translation to Spanish by a native Spanish speaker followed by back-translation into English by different bilingual speakers (40). All Los Angeles patients who were likely to be Latina based on hospital or surname-based census information were sent study materials in English and Spanish. The Spanish version of the survey was not sent to the Detroit patients because less than 5% of Detroit population is Hispanic or Latino (41), and thus, we suspected that there were very few monolingual Spanish-speaking patients in the metropolitan Detroit area.

The study protocol, including all human subject involvement, was approved by the institutional review boards of the University of Michigan, the University of Southern California, and Wayne State University. All participants received information about the purpose of the study, the risks and benefits of participation, and patient confidentiality. A waiver of documentation of signed informed consent was obtained from all participating-site institutional review boards.

Study Sample and Response Rate

During the study period, 3252 eligible patients were accrued, including 811 Latina patients, 920 African American patients, 1452 white patients, and 69 patients of other races and/or ethnicities (Figure 1). The accrued sample included approximately 70% of the Latina and African American patients and approximately 30% of non-Latina white patients diagnosed in the metropolitan areas of Los Angeles and Detroit during the study period. After initial physician and patient contact, 119 total patients were excluded for the following reasons: the physician refused permission to contact the patient ($n = 20$), the patient did not speak English or Spanish ($n = 17$), the patient was too ill or not competent to participate ($n = 59$), or the patient did not acknowledge that she had breast cancer ($n = 23$). Of the 3133 patients included in the final accrued sample, 432 (13.8%) could not be located or contacted and 411 (13.1%) patients were located and contacted but did not return the survey. Information from the survey was merged to Los Angeles and Detroit SEER data for all patients in the final sample. There were 22 respondents (0.6%) who completed the survey but the information they provided could not be merged to SEER data as an incident case and thus were excluded for nonresponse. Thus, the final sample included 2268 patients (72.4% response rate) of whom 96.5% completed a written survey and 3.5% completed a telephone survey.

The survey response rates were 73.5% for Latina patients, 66.4% for African American patients, and 74.2% for white patients ($P < .001$). Compared with respondents, nonrespondents were more likely to have stage II or stage III disease (43.4% vs 40.5%, $P = .005$) and were less likely to have received breast-conserving surgery (54.5% vs 63.2%, $P = .02$).

The analyses for this article included only women whose documented summary stage in SEER (35) was ductal carcinoma

in situ I or II because treatment guidelines state that both mastectomy and breast-conserving surgery with radiation are viable treatment options for these stages of breast cancer (42,43). Thus, we excluded women with stage IIIA or higher disease (n = 204). We also excluded women with a self-reported clinical contraindication to breast-conserving surgery with radiation (n = 250), such as those who had been treated with radiation or whose tumor was large relative to the size of the breast. An additional 119 women were excluded because they had both stage IIIA or higher disease and a self-reported clinical contraindication. We also excluded women (n = 44) who did not designate their racial or ethnic group or indicated “other” on the survey and whose race or ethnicity could not be determined from SEER. After these exclusions, the final analytic sample for this analysis was 1651 patients (Figure 1).

Outcome Measures

Our survey measures and analysis plan were guided by a conceptual framework of health-care utilization (44) and our previous work, which has focused on understanding the relationship between patient-physician communication and treatment use (24,25,45-47). Development of the patient survey was based on this framework and on extensive pilot testing (25,45-47). The primary outcome variable for this analysis was the initial surgical treatment the patient received (mastectomy vs breast-conserving surgery). This information was obtained by asking patients, “What was the first surgery that you had to remove your breast cancer after the biopsy test?” Respondents could choose mastectomy, lumpectomy (ie, breast-conserving surgery), or no more surgery. Those who chose lumpectomy were able to indicate that they then had no more surgery, had another lumpectomy, or eventually had a mastectomy.

There were two primary independent variables: patient involvement in the surgical treatment decision and patient race and ethnicity. Patient decision involvement was measured using the Control Preferences Scale developed by Degner et al. (48). The Control Preferences Scale is a widely used and validated (48,49) scale for measuring decision involvement that asks respondents to rate their actual involvement in a medical decision on a 5-point scale for which 1 = my surgeon made the decision with little input from me, 2 = my surgeon made the decision after seriously considering my opinion, 3 = my surgeon and I shared equally in the decision, 4 = I made the decision after seriously considering my surgeon’s opinion, and 5 = I made the decision with little input from my surgeon. We recoded this variable into three categories to describe the decision process as was done in previous work evaluating patient involvement in breast cancer treatment decision making (24,46,47): 1-2 = surgeon-based decision, 3 = shared decision, and 4-5 = patient-based decision.

Patient self-reported race and ethnicity was categorized into four groups: Latina-low acculturation, Latina-high acculturation, African American, or white. We classified the Latina patients as low or high in acculturation by using the Short Acculturation Scale for Hispanics developed by Marín et al. (50,51). The Short Acculturation Scale for Hispanics comprises a set of five questions that are based largely on the respondent’s language preferences, each of which are answered on a 5-point scale (1 = only Spanish, 2 = Spanish better than English, 3 = Spanish and English equally well, 4 = English better than Spanish, and 5 = only English). The Short Acculturation Scale for Hispanics has been widely used to evaluate acculturation in Hispanic populations (52,53). We have further evaluated the reliability of the Short Acculturation Scale for Hispanics by comparing it with other measures of acculturation, including the number of years the respondent has lived in the United States and the country of origin of the respondent’s mother and father (54). Other

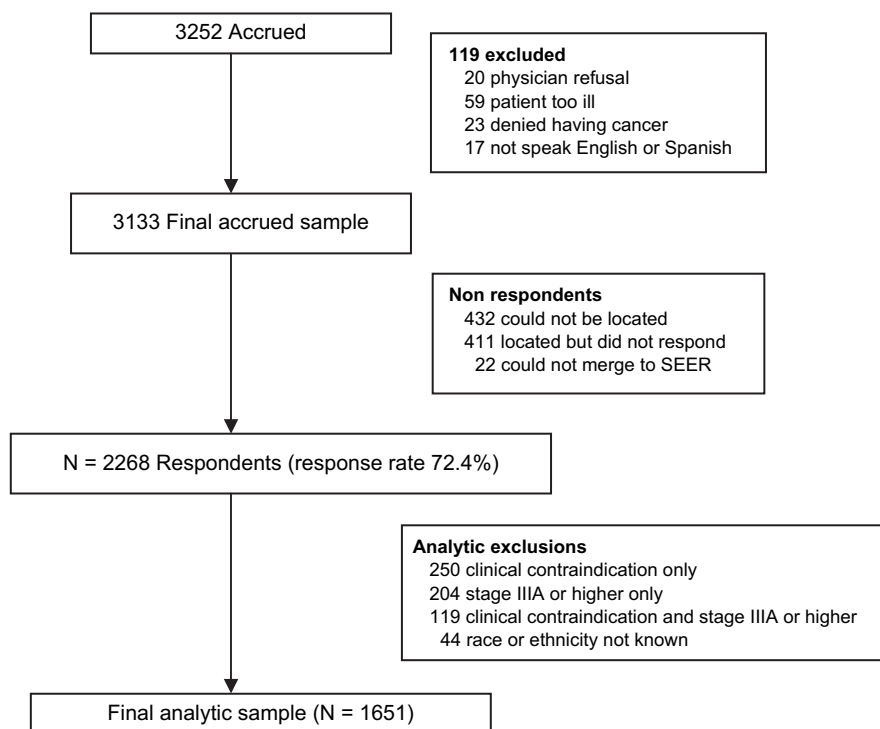


Figure 1. Study flow diagram. SEER = Surveillance, Epidemiology, and End Results.

patient demographic variables included age at diagnosis, highest completed education level (less than high school, high school graduate, some college, college graduate, or higher), marital status (married or partnered, not married), annual household income (<\$30 000, \$20 000–\$59 999, \$60 000–\$89 999, ≥\$90 000, missing) and type of health insurance (none, employer only, Medicare and/or Medicaid only, other). Age was evaluated in three categories (29–44, 45–64, or 65–79 years) as well as continuously. Cut points for income and age were chosen to ensure a relatively equal distribution in each category. The clinical variables used in the analysis were from the SEER record and included the tumor size in millimeters (<20, 20–39, >40 mm, missing), histological grade (35) (well differentiated, moderately differentiated, poorly differentiated, or unknown), and tumor behavior (ductal carcinoma in situ or invasive). Cut points for clinical factors were based on the SEER summary stage manual (35). These clinical variables were used in our analysis because they are generally available to both surgeons and patients at the time of the initial surgical consultation, whereas pathological stage is not available until after the biopsy.

We evaluated additional factors that we hypothesized might affect the association between patient decision involvement and receipt of mastectomy, including measures of patient attitudes regarding surgery and the role of others in the patient's decision-making process. Patient attitudes regarding surgery were assessed by asking patients to indicate the importance of issues related to cancer recurrence, radiation, and body image in their decision making about surgical treatment. For recurrence and body image, patients responded to three questions, each of which had a 5-point response scale (1 = not at all important, 2 = a little important, 3 = somewhat important, 4 = quite important, and 5 = very important). In each case, the responses to these three questions were summed to create one continuous measure (range: 3–15 points) that reflected the degree of importance of these issues in surgical treatment decision making. A 75% cut point was then used to create a two-level variable (ie, ≥75% of the summary score frequency distribution was considered quite or very important vs <75% considered not or a little important) describing the importance of recurrence and body image concerns in treatment decision making. The same procedure was used to create a two-level variable related to the importance of radiation concerns; however, only two questions rather than three were used to create the final variable.

We used four survey questions to evaluate the role of others in decision making. The first asked the respondent whether she had a friend or family member accompany her during the treatment consultation (yes, no). The remaining three questions asked the respondent to report how important her spouse (or partner), family, and friends were in her treatment decision on a 5-point scale in which 1 = not at all important, 2 = a little important, 3 = somewhat important, 4 = quite important, and 5 = very important. Each of these questions were then categorized to create three two-level variables reflecting the importance of the spouse, family, and friends (not at all, a little, or somewhat important [1–3] points) vs quite or very important [4–5 points]) in surgical treatment decision making.

Statistical Analysis

We first generated descriptive statistics for all of the variables. We then evaluated associations between race and ethnicity, the out-

come variable (receipt of mastectomy or breast-conserving surgery), and all independent variables. Analysis of variance was used to evaluate racial and ethnic differences in age at diagnosis, and χ^2 tests were used to test for differences by race or ethnicity in mastectomy use and in all other categorical independent variables. We compared the association between decision involvement and mastectomy use among the three racial and ethnic groups by using the χ^2 test. We also used the χ^2 test to compare the association between patient attitudes about surgery and mastectomy use among the racial and ethnic groups. All statistical tests were two-sided, and a *P* value less than .05 was considered statistically significant. We adjusted for design effects by applying a sample weight to the point estimates to account for differential selection by race, ethnicity, and nonresponse.

We used three logistic regression models to examine the independent effects of these factors on the odds of having a mastectomy as the initial surgical treatment. The variables included in model 1 were patient involvement in decision making and race or ethnicity, controlling for all other demographic and clinical factors. Model 2 additionally controlled for patient attitudes regarding recurrence, radiation, and body image, and model 3 additionally controlled for the four questions that measured the role of others in decision making. Wald χ^2 tests were used to evaluate the statistical significance of subsets of the coefficients for decision involvement and race or ethnicity (55). A final model controlled for all two-way interactions between race or ethnicity and the decision-involvement, attitudes-regarding-surgery, and the importance-of-others variables. Each model adjusted the SEs for clustering of patients within surgeons (56). We could not control for site (Los Angeles vs Detroit) because there were very few Latina patients in Detroit. All analyses were conducted using Stata software for Windows (version 10.0; StataCorp LP, College Station, TX). The odds ratios and 95% confidence intervals (CIs) generated by logistic regression were corrected as described by Zhang and Yu (57) to account for the fact that the incidence of the outcome of interest—mastectomy use—was greater than 10%; estimated relative risks (RRs) are presented.

Results

The mean time from the date of definitive surgical treatment and response to the survey was 9 months (SD = 3.2 months). The analytic sample (N = 1651) was 23.9% Latina (12.0% low acculturated, 11.9% high acculturated), 27.1% African American, and 48.9% white (Table 1). Among the patients with stage 0–II cancer and no contraindication to breast-conserving surgery with radiation, 17.2% received mastectomy (19.7% of the low-acculturated Latina patients, 19.3% of high-acculturated Latina patients, 13.0% of the African American patients, and 17.1% of the white patients; χ^2 statistic = 6.89, *P* = .142). Overall, 38.1% of women reported a shared surgical treatment decision, 34.4% reported a patient-based decision, and 27.5% reported a surgeon-based decision. Low-acculturated Latina patients reported a surgeon-based treatment decision more often than other patient groups (33.1% vs 26.7% for high-acculturated Latina patients, 26.2% for African American patients, and 24.0% for white patients; χ^2 statistic = 10.8, *P* = .096) (Table 1).

Table 1. Characteristics of the analytic sample by race and ethnicity (N = 1651)*

Characteristic	Low-acclulturated Latina (n = 198)	High-acclulturated Latina (n = 197)	African American (n = 448)	White (n = 808)	P†
Primary outcome					
Initial surgical treatment, %					
Mastectomy	19.7	19.3	13.0	17.1	
Breast-conserving surgery	80.3	80.7	87.0	82.9	.142
Independent variables					
Decision involvement, %					
Surgeon based	33.1	26.7	26.2	24.0	
Shared	37.4	33.5	40.4	41.1	
Patient based	29.5	39.8	33.4	34.9	.096
Mean age at diagnosis, y (SD)	55.4 (11.2)	56.4 (12.7)	57.3 (11.3)	58.6 (10.9)	.083‡
Education level, %					
Less than high school	71.2	21.8	15.0	6.3	
High school graduate	17.7	20.3	16.0	24.9	
Some college	8.6	39.6	41.5	35.5	
College graduate	2.5	18.3	26.6	33.2	<.001
Marital status, %					
Not married	40.9	42.1	58.0	38.0	
Married/partnered	59.1	57.9	42.0	62.0	<.001
Annual household income in \$, %					
<30 000	54.0	28.9	31.9	17.3	
30 000–59 999	13.6	25.4	25.7	24.9	
60 000–89 999	1.01	12.7	16.3	17.1	
≥90 000	0.51	16.2	10.7	23.4	
Missing	30.8	16.8	15.4	17.3	<.001
Insurance, %					
None	24.2	7.1	3.4	2.1	
Employer only	16.7	10.7	14.3	7.8	
State (Medicare and/or Medicaid)	13.6	30.5	37.1	30.8	
Other coverage	45.5	51.8	45.3	59.5	<.001
Tumor behavior, %					
DCIS	26.3	22.3	25.0	21.7	
Invasive	73.7	77.7	74.0	78.3	.543
Tumor size in mm, %					
<20	56.21	56.9	56.7	64.3	
20–39	27.7	27.9	29.2	24.0	
≥40	8.6	9.1	8.1	7.3	
Missing	7.6	6.1	6.0	4.3	.400
Quite/very important in decision making, %					
Recurrence	55.6	61.4	64.1	55.8	.044
Radiation	26.8	30.9	29.6	17.2	<.001
Body image	17.2	22.3	25.3	19.8	.010
Quite/very important role in decision making, %					
Spouse	54.3	59.3	44.5	51.6	.015
Family	75.9	49.4	50.3	34.1	<.001
Friends	45.4	18.2	25.6	13.7	<.001
Accompanied to surgery consultations, %	77.5	79.2	71.2	78.7	.032

* Includes those with stage 0–II breast cancer and no clinical contraindications to breast-conserving surgery with radiation. For some characteristics, the percentages do not total 100% because of rounding. DCIS = ductal carcinoma in situ.

† P values obtained from χ^2 tests (two-sided) except where indicated.

‡ P value obtained from analysis of variance.

Sample Characteristics

There was no statistically significant difference in the mean age at diagnosis between low- or high-acclulturated Latina patients and white patients (55.4 and 56.4 years, respectively, vs 58.6 years, $P = .083$) (Table 1). Low-acclulturated Latina patients were statistically significantly less likely than other patients to have some college or to be a college graduate ($P < .001$), to have an income in the highest bracket ($P < .001$), and to be insured ($P < .001$). African American patients were statistically significantly less likely to be

married or partnered than the other groups of patients ($P < .001$). There were no statistically significant differences in clinical factors (ie, tumor behavior, tumor size, or histological grade) among the four racial or ethnic groups.

Patient attitudes regarding surgery differed statistically significantly by race or ethnicity. Although all women reported that concerns about recurrence were important in their treatment decision making, African American women indicated that this issue was quite or very important more often than the other groups

(64.1% vs 55.6%, 61.4%, and 55.8% for low-accultured Latina patients, high-accultured Latina patients, and white patients, respectively; χ^2 statistic = 9.8, $P = .044$) (Table 1). White women were least likely to indicate that radiation concerns were quite or very important (17.2% vs 26.8%, 30.9%, and 29.6% for white patients vs low-accultured Latina patients, high-accultured Latina patients, and African American patients, respectively; χ^2 statistic = 37.5, $P < .001$) (Table 1). High-accultured Latina and African American patients reported that body image concerns were quite or very important in their treatment decision making more often than other groups (22.3% for high-accultured Latina patients and 25.3% for African American patients vs 17.2% for low-accultured Latina patients and 19.8% for white patients; χ^2 statistic = 13.2, $P = .01$) (Table 1).

Although most women reported having had a family member or friend accompany them during surgical consultations, African American women were least likely to report having been accompanied (71.2% vs 77.5%, 79.2%, and 78.7% for African American vs low-accultured Latinas, high-accultured Latinas, and white women, respectively; χ^2 statistic = 10.6, $P = .032$). African American women were the least likely to indicate that their spouse was very important in decision making (44.5% for African American vs 54.3% for low-accultured Latina patients, 59.3% for high-accultured Latina patients, and 51.6% for white patients; χ^2 statistic = 12.4, $P = .015$). Family was most important in decision making for low-accultured Latinas; 75.9% of low-accultured Latina women said family was very important in decision making compared with 49.4% of high-accultured Latina women, 50.3% of African American women, and 34.1% of white women ($P < .001$). Low-accultured Latina women were also much more likely to state that friends were very important in decision making compared with the other groups ($P < .001$).

Decision Involvement and Initial Mastectomy

We examined the proportion of respondents who received mastectomy initially by categories of decision involvement (surgeon based, shared, or patient based) and race or ethnicity (Figure 2).

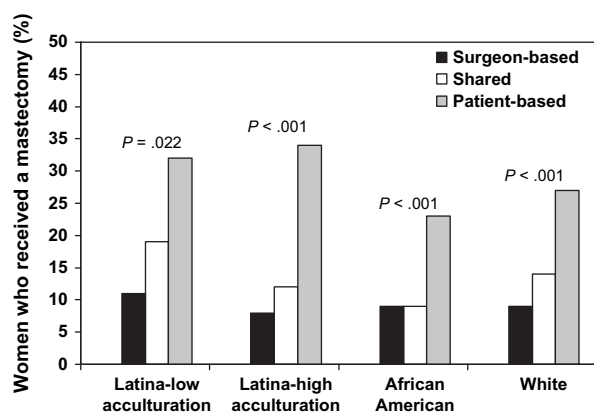


Figure 2. Association between patient involvement in decision making and receipt of mastectomy, by race and ethnicity. Includes women with stage 0–II breast cancer and no clinical contraindications to breast-conserving surgery with radiation ($N = 1651$). P values are based on χ^2 tests (two-sided) for differences in decision involvement and receipt of mastectomy for each racial or ethnic group.

For each racial or ethnic group, the proportion of women who received mastectomy initially was substantially greater among women who reported a patient-based decision compared with those who reported a shared or surgeon-based decision ($P = .022$ for low-accultured Latina patients, $P < .001$ for high-accultured Latina, African American, and white patients).

Patient Attitudes About Surgery and the Role of Others in Decision Making

We next examined the proportion of respondents who received initial mastectomy by patient attitudes about recurrence, radiation, and body image (Figure 3). Women who reported that concerns about recurrence and radiation were very important in their decision making received mastectomy statistically significantly more often than women for whom concerns about these issues were of little importance ($P = .003$ for recurrence, $P < .001$ for radiation). Conversely, those who were quite or very concerned about body image were less likely to receive initial mastectomy compared with those who were not very or moderately concerned ($P = .22$).

Women who had a friend or family member accompany them to the surgical consultation were statistically significantly more likely to receive initial mastectomy than those who attended the surgical consultation alone (18.5% vs 12.1%; χ^2 statistic = 8.5, $P = .004$). Women who said that their spouse was very important in decision making were statistically significantly less likely to receive initial mastectomy than those who indicated their spouse was not or a little important (14.5% vs 18.3%; χ^2 statistic = 3.5, $P = .063$). Women who said family or friends were very important in decision making were no more or less likely to receive mastectomy than those who said family or friends were not or a little important (data not shown).

Multivariable Regression

We used logistic regression models that adjusted for clustering of patients within specific surgeons to evaluate factors associated with initial mastectomy use after (Table 2). In model 1, which adjusted

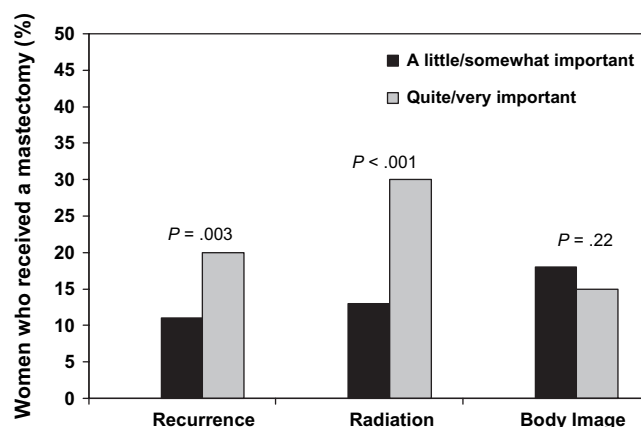


Figure 3. Association between patient attitudes about surgery and receipt of mastectomy. Includes women with stage 0–II breast cancer and no clinical contraindications to breast-conserving surgery with radiation ($N = 1651$). P values are based on χ^2 tests (two-sided) for differences in degree of importance of each attitude (not/a little vs quite/very important) in surgical decision making and receipt of mastectomy.

Table 2. Logistic regression modeling of factors associated with initial receipt of mastectomy (N = 1651)*

Factor	Model 1, RR (95% CI)	Model 2, RR (95% CI)	Model 3, RR (95% CI)
Decision involvement			
Surgeon based	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
Shared	1.35 (0.99 to 1.59)	1.33 (0.91 to 1.88)	1.37 (0.87 to 2.03)
Patient based	2.58 (2.02 to 3.16)	2.53 (1.92 to 3.16)	2.77 (2.05 to 3.81)
Wald χ^2 statistic (<i>P</i>)	55.65 (<.001)	52.32 (<.001)	52.02 (<.001)
Race/ethnicity			
White	1.00 (Referent)	1.00 (Referent)	1.00 (Referent)
Latina-low acculturation	1.21 (0.74 to 2.09)	1.11 (0.66 to 1.74)	1.24 (0.70 to 2.00)
Latina-high acculturation	1.04 (0.66 to 1.56)	0.92 (0.57 to 1.41)	0.92 (0.54 to 1.46)
African American	0.72 (0.49 to 1.03)	0.60 (0.41 to 0.89)	0.58 (0.37 to 0.86)
Wald χ^2 statistic (<i>P</i>)	4.67 (.213)	8.79 (.063)	9.07 (.061)
Quite/very important in decision making			
Recurrence concerns	—	1.66 (1.28 to 2.10)	1.80 (1.22 to 2.34)
Radiation concerns	—	2.35 (1.88 to 2.85)	2.22 (1.70 to 2.79)
Body image concerns	—	0.47 (0.30 to 0.74)	0.55 (0.33 to 0.86)
Quite/very important role in decision making			
Spouse	—	—	0.53 (0.36 to 0.78)
Family	—	—	1.05 (0.77 to 1.53)
Friends	—	—	1.04 (0.66 to 1.56)
Accompanied to surgery consultations	—	—	1.62 (1.14 to 2.21)

* Includes women with stage 0–II breast cancer and no clinical contraindications to breast-conserving surgery with radiation. All logistic regression models were adjusted for age at diagnosis, education level, annual household income, insurance status, tumor behavior, tumor size, and tumor histology, and SEs were adjusted for clustering within surgeons. The variables included in model 1 were patient involvement in decision making and race or ethnicity, controlling for all other demographic and clinical factors. Model 2 additionally controlled for patient attitudes regarding recurrence, radiation, and body image, and model 3 additionally controlled for the four questions that measured the role of others in decision making. Odds ratios and 95% confidence intervals were corrected to approximate the risk ratio as described by Zhang and Yu (57). — = not applicable. CI = confidence interval; RR = risk ratio.

for demographic and clinical factors, women who reported a patient-based decision were more than twice as likely as those who reported a surgeon-based decision to have received initial mastectomy (estimated RR = 2.58, 95% CI = 2.02 to 3.16). Women who reported a shared decision were somewhat more likely to have received a mastectomy than those who reported a surgeon-based decision (estimated RR = 1.35, 95% CI = 0.99 to 1.59), but this association was not statistically significant. Patient involvement in decision making was statistically significantly associated with the initial receipt of mastectomy (Wald χ^2 statistic = 55.65, *P* < .001), whereas race or ethnicity was not (Wald χ^2 statistic = 4.67, *P* = .213).

In model 2, inclusion of each of the patient attitudes did not substantially affect the association between patient decision involvement and receipt of mastectomy, even though each patient attitude was independently associated with receipt of initial mastectomy. For example, women who reported that concerns about recurrence or radiation were very important in their treatment decision making were statistically significantly more likely to receive mastectomy initially than those who reported that these factors were of less or moderate importance (for concerns about recurrence, estimated RR = 1.66, 95% CI = 1.28 to 2.10; for concerns about radiation, estimated RR = 2.35, 95% CI = 1.88 to 2.85). Conversely, women who reported that concern about body image was a very important factor in their surgery decision were statistically significantly less likely to receive mastectomy initially than those who reported that concern about body image was of less or moderate importance (estimated RR = 0.47, 95% CI = 0.30 to 0.74).

In model 3, which additionally controlled for the role of others in the woman's decision making, women who said their spouse's opinion was very important to their decision making were statistically significantly less likely to receive initial mastectomy than

those who placed less weight on their spouse's opinion (estimated RR = 0.53, 95% CI = 0.36 to 0.78). However, there was no statistically significant association between the importance of the opinions of family or friends and receipt of initial mastectomy. Having a family member or friend accompany the woman during surgical consultations was statistically significantly and positively associated with receipt of initial mastectomy (estimated RR = 1.62, 95% CI = 1.14 to 2.21). Inclusion of these factors into model 3 also did not substantially alter the association between patient involvement in decision making and mastectomy use. All statistically significant associations between independent variables and mastectomy use remained the same in terms of effect size and level of statistical significance as those in model 3, when the analyses were restricted to women who were married or partnered (data not shown). None of the two-way interactions was statistically significant (data not shown); therefore, the models are presented without the addition of these interaction terms.

Discussion

Consistent with our hypothesis that more patient involvement in decision making would be associated with greater receipt of mastectomy, greater self-assessed patient involvement in surgical treatment decision making was statistically significantly associated with the receipt of mastectomy as the initial surgical procedure of definitive intent. Our study also showed an association between more patient involvement in decision making and receipt of mastectomy in all four racial or ethnic groups. We found that patient attitudes about recurrence, radiation, and body image were associated with initial mastectomy use and that the patient's family and friends may affect their decision-making process. Our results suggest that for

some women, the choice of mastectomy is based on personal preferences for the procedure, thus bringing into question the use of breast-conserving surgery with radiation as a quality indicator for treatment of early-stage breast cancer (5–7,58).

Although a number of studies have documented the variation in patient involvement regarding decision about treatment for breast cancer (19–27), only a few (25,27) have evaluated the association between patient decision involvement and initial treatment utilization and none has included large samples of Latinas. Moreover, the results from research linking decision making to treatment use have been mixed. For example, Mandelblatt et al. (27) found that younger breast cancer patients and those who were accompanied to treatment appointments more often reported a shared surgical treatment decision process but that a shared treatment decision was not associated with treatment utilization. By contrast, Katz et al. (25) found that greater patient involvement in decision making was associated with greater use of mastectomy, which is consistent with our results. Our results differ from those of Katz et al. in that we observed a strong association between patient-reported involvement in surgical decision making and receipt of mastectomy for all racial and ethnic groups, including less acculturated Latinas, whereas Katz et al. observed this association primarily for whites. Our study also expands on their results in that we found that patient concerns about recurrence, radiation, and body image were associated with surgical choice in a larger, more diverse sample. Although both studies used the same measures of patient attitudes about surgical decision-making process (ie, concerns about recurrence, radiation, and body image), the differing results may reflect the fact that we focused on decision making for the initial surgical treatment, had more precise measures of clinical contraindications to the different surgery options, and included a large sample of Latinas, both low and highly acculturated.

Our results are also consistent with recent work by Collins et al. (28), which showed that patient choice of mastectomy was associated with the desire for peace of mind and to avoid radiation. Collins et al. also found that women who valued keeping their breast more often chose breast-conserving surgery with radiation, similar to our result that concern about body image was associated with lower receipt of mastectomy and greater receipt of breast-conserving surgery. Fear of recurrence has also been associated with mastectomy use in two smaller studies (59,60). These studies and our results suggest that some women make a patient-driven decision about having a mastectomy that is based on issues that are important to them. However, because not all treatment decisions are made based on accurate knowledge about treatment risks and benefits (47), it is important to ensure that patient-based decisions are both value based and informed (61). Although decision tools have been shown to improve patients' knowledge about breast cancer treatment options (62), incorporating patients' values into these tools remains a challenge (28).

To our knowledge, this is the first study to evaluate the role of the patient's family and friends in decision making and receipt of surgery for breast cancer. We found that women of different racial and ethnic backgrounds indicated that the opinions of their spouse, family, and/or friends were important in their decision making about surgical treatment and that less acculturated Latinas placed

the most importance on others' opinions. Several studies have found that an accompanying person is an important source of support for patients in surgical consultations (63–65), but the association between the influence of others and treatment utilization has not been well explored. Some studies suggest that spouses play a role in breast cancer treatment decisions (63,64), but those studies were limited by small samples and the results were not linked to actual treatment choices. Our results suggest that a substantial proportion of women take their spouse's opinion into account when making treatment decisions and that those opinions may influence the woman's choice of treatment. Thus, spouses have a potentially important role in treatment discussions with the provider. In addition, our finding that having a family member or friend present during surgical consultations was associated with receipt of mastectomy initially also suggests that others may play an important role in shaping treatment discussions and, ultimately, decisions.

This study has some limitations. First, the measures used in this analysis came from patient self-report and may be subject to recall bias. Second, this study was cross-sectional and thus we could only examine associations between independent variables and the outcomes of interest. Third, this study was conducted in two geographic locations and the survey was only administered to women who could speak English or Spanish; therefore, the results may not be generalizable to other women with breast cancer. In addition, we could not control for site effects because of the insufficient numbers of Latinas in Detroit. Although we controlled for the effects of individual surgeons on the results, we were not able to control for other system factors, such as the treating hospital. We also could not evaluate decision making among Latina subgroups (eg, Mexican or Puerto Rican women). Finally, some measures, such as decision involvement and patient attitudes, have not been validated in Spanish-speaking populations.

Despite these limitations, our findings confirm that patient involvement in decision making has important implications for surgical choices among breast cancer patients. Furthermore, patients' attitudes about disease recurrence, the effects of radiation, and the impact of surgery on body image play a powerful role in their treatment decisions. To ensure that these decisions are fully informed, surgeons must communicate information about the risks and benefits of all options, while also helping patients clarify their own treatment preferences (28,61). Doing so may be particularly challenging for providers when their patients face language or acculturation barriers. Our finding that most patients arrive at their first consultation with a family member or friend suggests an opportunity for clinicians to deliver information to individuals who may play a key role in helping patients make treatment decisions. Furthermore, given that many patients, particularly less acculturated Latinas, reported that they relied on their family or friends for help in decision making, an approach to decision making that involves the patient and her important sources of support may improve the delivery of complex treatment information. Decision tools directed to patients and those involved in decision making, such as family members and friends, may improve patients' understanding of the issues related to recurrence and treatment effects and help patients clarify their decision preferences.

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Funding

R01-CA109696 and R01-CA08870 from the National Cancer Institute to the University of Michigan. S.J.K. was supported by an Established Investigator Award in Cancer Prevention, Control, Behavioral, and Population Sciences Research from the National Cancer Institute (K05CA111340).

Notes

The study sponsors did not have any role in the design of the study; the collection, analysis, or interpretation of the data; the writing of the manuscript; or the decision to submit the manuscript for publication.

The authors do not have any conflict of interest to disclose, including any financial, personal, or other relationship within 3 years of beginning this study, which could inappropriately influence, or be perceived to influence, this work.

The collection of Los Angeles County cancer incidence data used in this study was supported by the California Department of Public Health as part of the state-wide 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-35139 awarded to the University of Southern California, contract N01-PC-54404 awarded to the Public Health Institute; and the Centers for Disease Control and Prevention's National Program of Cancer Registries, under agreement IU58DP00807-01 awarded to the Public Health Institute. The collection of metropolitan Detroit cancer incidence data was supported by the National Cancer Institute's Surveillance, Epidemiology, and End Results Program contract N01-PC-35145.

The ideas and opinions expressed herein are those of the author(s) and endorsement by the State of California; Department of Public Health, National Cancer Institute; and the Centers for Disease Control and Prevention or their contractors and subcontractors is not intended nor should be inferred.

We thank the American College of Surgeons Commission on Cancer (particularly David Winchester, MD, and Connie Bura) for their endorsement of our research. We acknowledge the outstanding work of our research staff, Paul Abrahamse and Ashley Gay. We would also like to acknowledge the breast cancer patients who responded to our survey. Special thanks to Ain Boone, Cathey Boyer, and Deborah Wilson for their data collection efforts at the Metropolitan Detroit Cancer Surveillance System and to Alma Acosta, Marlene Caldera, Norma Caldera, Maria Isabel Gaeta, Urduja Trinidad, and Mary Lo at the Cancer Surveillance Program in Los Angeles.

Manuscript received January 19, 2009; revised July 6, 2009; accepted July 16, 2009.