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ORIGINAL REPORT

Patient Involvement in Surgery Treatment Decisions for Breast Cancer

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ABSTRACT

Purpose
High rates of mastectomy and marked regional variations have motivated lingering concerns about overtreatment and failure to involve women in treatment decisions. We examined the relationship between patient involvement in decision making and type of surgical treatment for women with breast cancer.

Methods
All women with ductal carcinoma-in-situ and a 20% random sample of women with invasive breast cancer aged 79 years and younger who were diagnosed in 2002 and reported to the Detroit and Los Angeles Surveillance, Epidemiology, and End Results registries were identified and surveyed shortly after receipt of surgical treatment (response rate, 77.4%; n = 1,844).

Results
Mean age was 60.1 years; 70.2% of the women were white, 18.0% were African American, and 11.8% were from other ethnic groups. Overall, 30.2% of women received mastectomy as initial treatment. Most women reported that they made the surgical decision (41.0%) or that the decision was shared (37.1%); 21.9% of patients reported that their surgeon made the decision with or without their input. Among white women, only 5.3% of patients whose surgeon made the decision received mastectomy compared with 16.8% of women who shared the decision and 27.0% of women who made the decision ($P < .001$, adjusted for clinical factors, predisposing factors, and number of surgeons visited). However, this association was not observed for African American women (Wald test 10.0, $P = .041$).

Conclusion
Most women reported that they made or shared the decision about surgical treatment. More patient involvement in decision making was associated with greater use of mastectomy. Racial differences in the association of involvement with receipt of treatment suggest that the decision-making process varies by racial groups.

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INTRODUCTION

Although there is professional consensus that most women with early-stage breast cancer are good candidates for breast-conserving surgery (BCS),[1-3] more than one third of women with early-stage breast cancer were treated with mastectomy in 2001.[4] This persistent trend has raised concerns about overtreatment. Additionally, marked regional variations in these procedures[5-8] have suggested that surgeons may not be uniformly adhering to treatment guidelines.[9-12] Several observers have suggested that large variation in patterns of surgical treatment for breast cancer is evidence of failure to involve women in making the decision about the treatment they prefer.[13-15] In response to concerns about overtreatment and lack of patient involvement, 20 states have passed laws mandating that surgeons provide information about the surgical treatment options for breast cancer.[16-18]

Despite the attention paid to this issue, little is known about how surgical decisions about breast cancer treatment are made. Surgical treatment decision making for breast cancer involves an interplay between patients, their providers, and family members.[8,19-21] Surgeons may recommend mastectomy because of a clinical contraindication to BCS, such as multicentric or multifocal disease, or because the removal of a large tumor would result in poor cosmesis.[2,22,23] Additionally, some surgeons may continue to harbor the opinion that mastectomy is clinically superior to BCS particularly because of the lower risk of local disease recurrence.[24] Patient preferences also play an important role in surgical treatment decisions. Patients may prefer mastectomy over BCS because of concerns about recurrence of disease, recovery from surgery, or side effects of radiation treatment.[21,24,25]

To examine patient perspectives about these issues in the surgical treatment decision-making process, we conducted a large population-based survey of women recently diagnosed with breast cancer in Detroit and Los Angeles. The aims of this study were as follows: (1) to explore patient perceptions about involvement in the surgical treatment decision; (2) to define the association between patient involvement in decision making and the type of surgery received; and (3) to determine whether particular patient attitudes and preferences were associated with surgery type and whether these associations differed by race.

METHODS

Study Population

Women aged 79 years and younger who were diagnosed with ductal carcinoma-in-situ (DCIS) and invasive breast cancer and identified by the Surveillance, Epidemiology, and End Results (SEER) Cancer Registries of the greater metropolitan areas of Detroit and Los Angeles during a 14-month period from December 2001 to January 2003 were eligible for the study.

Database and Sampling

We prospectively selected all patients with DCIS (to ensure adequate representation) and a random sample of invasive patients (oversampling African American women) each month to be included in the preliminary study sample (n = 2,647). Eligible patients had a primary diagnosis of breast cancer, underwent a definitive surgical procedure, resided in the catchment area of the SEER site, and were able to complete a questionnaire in English or Spanish. All Asian women and all US-born women younger than 50 years of age diagnosed with invasive disease in Los Angeles during our study period were excluded because these women were already being enrolled onto other studies. Women with a diagnosis of lobular carcinoma-in-situ were excluded because the natural history of and recommended treatment for this disease are different than for DCIS. Ninety percent of all accrued patients were eligible for the study (n = 2,382). The survey was completed by 77.4% of eligible patients (92.4% completed a written survey, and 7.6% completed an abbreviated telephone survey; n = 1,844).

Data Collection and Management

Physicians were notified of our intent to contact patients followed by an introductory letter and a telephone call to potential patients to assess eligibility. A questionnaire and grocery gift certificate worth $10 were mailed to all eligible women who agreed to participate and to people who could not be reached by phone (approximately 14% of potential respondents). The Dillman survey method was used to encourage response.[26]

SEER clinical data from hospital-based sources (tumor size, node status, regional and distant extension, histologic grade, and treatment information) were merged with survey data for 98.2% of patients. The study protocol was approved by the Institutional Review Boards of the University of Michigan, the University of Southern California, and Wayne State University.

Measures

The main dependent variable was type of surgical treatment received, either mastectomy (unilateral or bilateral) or BCS. Self-report of surgical treatment was used for all patients except when self-report was ambiguous or missing (n = 26), in which case SEER data were used. As observed in other studies,[8] we found that self-report and SEER data yielded the same surgical procedure for 96.3% of patients in our sample. Excluding patients for whom self-report and SEER data conflicted (n = 67) did not change the results.

The principal independent variables were measures of patient involvement in surgical decision making (perceptions of decision control adapted from Degner et al[27] and information exchange). Patients were asked to indicate which of the following statements best indicated how the surgery decision was made for their breast disease: (1) “My doctor(s) made the surgery decision with little input from me”; (2) “My doctor(s) made the surgery decision but seriously considered my opinion”; (3) “My doctor(s) and I made the surgery decision together”; (4) “I made the surgery decision after seriously considering my doctor(s) opinion”; or (5) “I made the surgery decision with little input from my doctor(s).” Information exchange was measured by asking patients if their surgeon described both BCS and mastectomy. Response categories were yes, no (he/she only described BCS), no (he/she only described mastectomy), and don’t remember.

Additional independent variables included clinical factors. Summary cancer stage was classified using the American Joint Committee on Cancer TNM staging system for breast cancer.[28] Tumor classification, tumor size, and histologic grade were derived from the SEER clinical data. A count of medical comorbidities was based on a list of seven common chronic conditions selected from the 2001 National Health Interview Survey that have been shown to be valid measures by self-report (chronic bronchitis or emphysema, coronary artery disease, congestive heart failure, diabetes, high blood pressure, stroke, and arthritis).[29-31] The presence of clinical contraindications to BCS or mastectomy was determined by evaluating patient reports of reasons their surgeon gave them for recommending one procedure over the other. Women were asked whether they received a recommendation for one procedure and the reasons for the recommendation as an open-ended question. Two clinicians (S.J.K. and M.M.) evaluated the responses and coded clinical contraindications to BCS if the reasons were the following: (1) large tumor and small breast; (2) diffuse, multicentric, or multifocal disease; (3) extension to skin or chest wall; (4) inability to obtain negative margins with BCS; or (5) contraindication to radiation therapy because of medical illness. Patient inability to undergo general anesthesia was considered a contraindication to mastectomy. Agreement between the two clinician observers based on evaluation of 200 patients was high ($\kappa = .87$).

The surgical decision-making context was described using the following variables: number of surgeons consulted, total number of visits before surgery, the timing of the surgical decision, and whether a surgeon recommended a procedure or made no recommendation. Predisposing variables included age, race, education, and marital status.

A variety of patient concerns and attitudes have been shown to influence decisions about surgery options.[21,27,32-34] We gathered information on 23 such items by asking women who perceived they had a choice between surgical procedures (71.2% of respondents), "When you were deciding between mastectomy and BCS, how much was your decision influenced by whether the treatment you chose would. . ."; followed by an individual item (examples included: keep you from worrying about the disease coming back, allow you to avoid exposing yourself to radiation, and not interfere with your sex life in the long term). From these items, we conducted factor analyses and subsequently constructed four scales indicating concerns about disease recurrence risk (four items, $\alpha = .85$), radiation effects (three items, $\alpha = .95$), recovery from surgical treatment (four items, $\alpha = .80$), and body/sexuality issues (four items, $\alpha = .84$). Summary scale scores were interval measures that ranged from 1 (not influenced by attitude factor) to 4 (greatly influenced by the factor). We collapsed these scales into the following three categories: not influenced/slightly influenced (scores from 1 to 2.3), moderately influenced (scores from 2.4 to 3.3), and greatly influenced (scores from 3.4 to 4.0).

Analysis

Analyses were restricted to patients with stage 0, I, and II disease (n = 1,629). We calculated proportions of patients who received mastectomy by decision involvement categories and ethnic groups, adjusting for clinical factors that were likely to be known at the time of the surgical decision (medical comorbidity, invasive carcinoma or DCIS, tumor size, and histologic grade), predisposing factors, the number of surgeons visited, and SEER site. Differences in adjusted proportions between groups were tested using Wald tests calculated using logistic regression. To examine the association between patient attitude scores and surgery type, we regressed receipt of mastectomy on scale score categories controlling for clinical and predisposing factors and SEER site to calculate adjusted proportions, testing for significance using Wald tests. All analyses were evaluated for second-order interactions between selected covariates, with special attention paid to ethnic groups and other covariates. Point estimates were adjusted for design effects by using a sample weight that accounted for differential selection by stage, ethnicity, and nonresponse; variance calculations accounted for patient clustering by surgeon.

RESULTS

Compared with survey respondents, nonrespondents were of similar age. However, nonrespondents were less likely to be white compared with respondents (69.4% *v* 76.6%, respectively; $P < .001$), were more likely to have stage II disease (25.2% *v* 20.4%, respectively; $P = .034$), and were more likely to have received a mastectomy (34.7% *v* 30.0%, respectively; $P = .021$).

Sample Characteristics

Table 1 shows the weighted distribution of the characteristics of the patient sample for women with American Joint Committee on Cancer stage 0, I, and II disease. The mean age was 60.1 years; 70.2% of women were white, 18.0% were African American, and 11.8% were other ethnic categories. About one third of the patients had some college experience or were college graduates, and 58.0% were married. Three quarters of the patients had invasive carcinoma. Approximately two thirds of the women had one or more medical comorbidities. Mastectomy was performed on 30.0% of patients with DCIS and 30.6% of patients with invasive cancer. Approximately 10% of women reported a clinical contraindication to BCS, whereas only one patient reported a contraindication to mastectomy.

Table 1. Study Sample Characteristics

Characteristic	% of Patients*
Mean age, years	60.1
Race	
White	70.2
Black	18.0
Other	11.8
Education	
College graduate or more	12.8
Some college	23.3
High school graduate	36.8
< High school	27.1
Married or partnered	58.0
Medical comorbidities	
0	41.0
1	28.9
2	20.1
3 or more	10.0
Tumor behavior	
DCIS	22.7
Invasive	77.2
Tumor size	
< 1 cm	31.6
1-2 cms	43.8
> 2 cms	24.6
Histology grade	
Low	24.7
Moderate	40.7
High	34.6
Clinical contraindication to BCS	11.5
Mastectomy	
DCIS	30.0
Invasive	30.6

Abbreviations: DCIS, ductal carcinoma-in-situ; BCS, breast-conserving surgery.

*Percentage weighted to account for differential selection by stage and race and nonresponse.

Table 2 shows the weighted distribution of decision context variables. Approximately one third of patients saw two or more surgeons. Approximately one quarter of patients had one visit before surgery, 39.6% had two visits, and 32.9% had three or more visits. Half of the patients reported that the surgery decision was made during the first visit, whereas 44.6% of patients reported that the decision was made after the first visit. Almost half of the patients reported that their surgeons recommended BCS; 15.2% of patients reported that their surgeons recommended mastectomy; and 37.2% of patients reported that their surgeon did not recommend one procedure over the other.

Table 2 also shows that, compared with white women, African American women reported seeing more surgeons (40.0% reported seeing two or more surgeons *v* 27.6% of white women; $P < .001$) and having had more visits before surgery (47.2% reported three or more visits *v* 27.2% of white women; $P < .001$). In addition, African American women were more likely to have made the surgical decision after the first visit (57.0% of African American women *v* 41.9% of white women; $P < .001$). Findings were consistent across tumor behavior (DCIS *v* invasive disease).

Results pertaining to decision control suggested that, at least among whites, more patient involvement in the surgical decision was strongly associated with receipt of mastectomy. Figure 1 shows the proportion of patients who received a mastectomy by decision control and ethnicity categories adjusted for age, education, marital status, number of surgeons visited, medical comorbidity, tumor behavior, tumor size, histologic grade, and SEER site. Analyses are restricted to women with stage 0 to II disease with no reported contraindication to either BCS or mastectomy (n = 1,422). Overall, most women reported that they made the surgical decision (41.0%) or that the decision was shared (37.1%). However, 21.9% of patients reported that their surgeon made the decision with or without their input. Figure 1 shows that there was a strong positive association between patient involvement in decision making and receipt of mastectomy among white women; only 5.3% of women who reported that their surgeon made the decision received mastectomy compared with 16.8% of women who reported that they shared the decision and 27.0% of women who reported that they made the decision ($P < .001$, adjusted for clinical factors, predisposing factors, and number of surgeons visited). This association was not consistent across ethnic groups (Wald test 10.0, $P = .041$, for interaction between ethnicity and decision control). In particular,

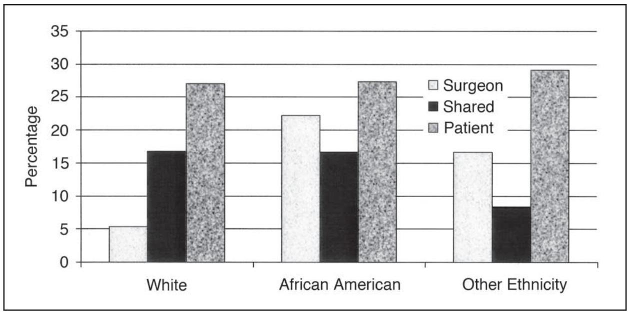

Fig 1. Receipt of mastectomy by decision control and race for women who did not report a clinical contraindication (n = 1,422). Figure is adjusted for age, marital status, education, number of surgeons visited, medical comorbidity, tumor behavior, tumor size, histologic grade, and Surveillance, Epidemiology, and End Results site. Interaction between racial groups and decision control groups is significant (Wald test 10.0, $P = .041$).

Table 2. Surgical Decision Context

Variable	White Patients (%)	African American Patients (%)	Other Patients (%)	All Patients (%)
No. of surgeons				
One	72.4	60.0	64.9	69.3
Two	23.1	32.5	27.5	25.3
Three or more	4.5	7.5	7.6	5.4
No. of visits				
One	32.3	16.9	20.5	27.5
Two	40.4	35.9	40.5	39.6
Three or more	27.2	47.2	39.0	32.9
Timing of decision				
Before first visit	5.5	4.5	6.4	5.2
At first visit	52.6	38.5	50.5	50.2
After first visit	41.9	57.0	43.1	44.6
Surgeon recommended*				
Neither mastectomy or BCS	35.3	43.9	44.5	37.2
Mastectomy	13.1	15.4	15.5	15.2
BCS	51.6	41.7	41.0	48.6

NOTE. Ethnic differences were significant for all variables ($P < .001$).
Abbreviation: BCS, breast-conserving surgery.
*Adjusted for age, education, and clinical factors (n = 1,629).

African American women were more likely to have received mastectomy compared with the other ethnic groups when the decision was perceived to have been made by the surgeon.

This greater likelihood of receipt of mastectomy for African American women compared with white women seemed to be related to ethnic differences in perceptions of communication with surgeons. Among women who reported that their surgeon made the decision about surgical treatment, 50.7% of whites reported that their surgeon described only BCS compared with 31.4% and 26.0% of African American women and other ethnic women, respectively ($P = .029$, adjusted for clinical and predisposing factors). These findings were consistent across tumor behavior.

Figure 2 shows the extent to which patient concerns about disease recurrence, radiation effects, recovery from surgical treatment, and body image or sexuality issues influenced their surgical treatment decision among the 66.2% of women who reported that they perceived a choice between surgical treatment options (n = 1,079). Concern about disease recurrence was the most influential factor; 39.6% of women reported that their treatment choice was greatly influenced by this concern. Concerns about recovery from surgical treatment were expressed by many women, followed by concerns about body image and sexuality and the effects of radiation.

Figure 3 shows the adjusted proportion of women who received a mastectomy based on the extent to which their treatment choice was influenced by concerns about disease recurrence, radiation effects, recovery from surgical treatment, and body image or sexuality issues. Concerns about disease recurrence and radiation effects highly favored receipt of mastectomy. For example, only 18.6% of women who were not influenced or slightly influenced by concerns about disease recurrence received mastectomy compared with 52.3% of women who reported being greatly concerned about disease recurrence ($P < .001$). As expected, results show that the level of concern about body image and sexuality issues was inversely associated with mastectomy; 34.0% of women who were not influenced or only slightly influenced by concerns about body image and sexual functioning received mastectomy compared with 16.6% of women who reported that they were greatly concerned about these issues ($P = .021$).

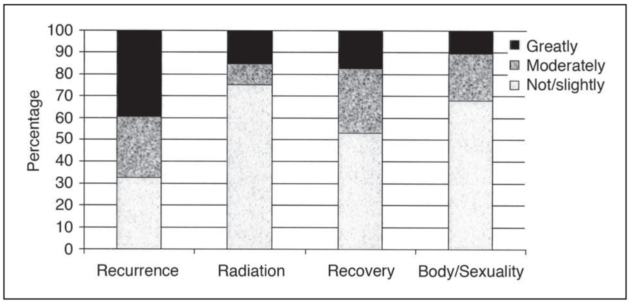

Fig 2. Level of patient concern by dimension for patients who perceived having a choice between surgical treatment alternatives (n = 1,079). Columns show the proportion of patients whose treatment decision was not/slightly, moderately, or greatly influenced by the given treatment-related concerns.

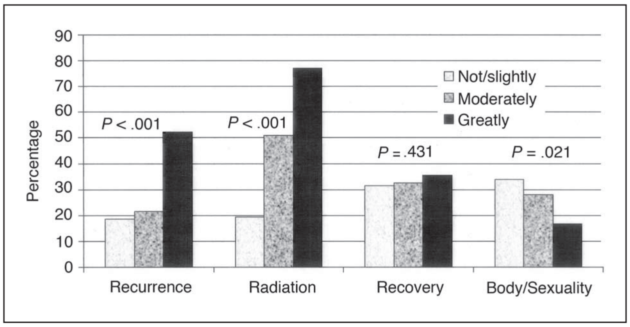

Fig 3. Receipt of mastectomy by level of patient concern for women who perceived having a choice between surgical treatment alternatives (n = 1,079). Levels indicate patient groups defined by whether their surgical decision was not/slightly, moderately, or greatly influenced by the given issue. Figure is adjusted for age, education, ethnicity, medical comorbidity, tumor behavior, tumor size, histologic grade, and Surveillance, Epidemiology, and End Results site.

DISCUSSION

In this population-based study of patients with breast cancer in two large metropolitan areas, we found that the majority of women (79.1%) reported that they made the decision about surgical treatment or that the decision was shared with their surgeon. Contrary to tacit beliefs, more patient involvement in surgical decision making was associated with a greater likelihood of receiving mastectomy. For example, one third of white patients who reported that they made the surgical decision received a mastectomy compared with fewer than 10% of white patients who reported that the surgeon had made the decision. Patient attitudes were strongly associated with surgical treatment type. Many patients reported that recurrence of disease and effects of radiation greatly influenced their decision, and these concerns favored the preference for mastectomy.

Our findings show that surgeons played a central role in the decision-making process and that they generally favored BCS. Approximately three quarters of patients reported receiving a surgeon recommendation for a specific procedure, and most of these women received the procedure that was recommended. Several lines of evidence in our study suggest that surgeons strongly favored BCS. First, nearly one fifth of patients reported that their surgeon only described BCS, whereas only approximately 3.5% of women reported that their surgeon only described mastectomy. Second, approximately half of women reported that their surgeon recommended BCS, and only a single subject reported a clinical contraindication to mastectomy. In contrast, only approximately 15% of women reported that their surgeon recommended mastectomy, and many of these women reported a clinical contraindication to BCS.

We found marked ethnic differences in women's perspectives and experiences with breast cancer surgical treatment decision making. Compared with white women, African American women visited more surgeons, had more visits before surgery, and were less likely to have made the surgical decision during the first consultation. Furthermore, African American women reported receiving less information about BCS. Moreover, although surgeon decision control was strongly associated with receipt of BCS for white women, this association was less evident for African American women. In fact, African American women were more likely to have received mastectomy compared with the other ethnic groups when the decision was perceived to have been made by the surgeon.

We can only speculate about the factors underlying these ethnic differences in treatment experiences and perspectives. Surgeons seem to place less emphasis on BCS when describing surgical options and making recommendations about surgery to African American women compared with white patients. This may be the result of unmeasured clinical factors that motivated surgeons to believe that some African American patients were poorer candidates for BCS. It may also be related to less optimal engagement about patients' desires and expectations for surgical treatment. The fact that African American women visited more surgeons, had more visits, and delayed the surgical decision compared with white women suggests that there is more decision uncertainty among African American women.

Taken together, these findings suggest that, for white women, who represent more than 80% of incident breast cancer patients in the study catchment areas and in the United States,[4] most patients with early-stage breast cancer received feedback from surgeons that BCS is preferable to mastectomy. For these women, more patient involvement in decision making was associated with a greater likelihood of receiving mastectomy. This association seemed to be largely related to patient concerns about disease recurrence risk and, to a lesser extent, concerns about radiation exposure and recovery from surgical treatment.

We only assessed patient perspectives regarding the treatment decision-making process. We do not know what actually occurred during visits or whether clinician perspectives differ from those of their patients. Additionally, we did not have adequate information about some patient, provider, and organizational attributes that may have affected treatment and the treatment experience. In particular, information about medical insurance was limited because less than 2% of patients in our sample reported no insurance, and we did not have specific information about coverage for breast cancer treatments (eg, reconstruction). We could have underestimated clinical contraindications to BCS because our criteria were conservative and patient reports may have been imprecise. Including women who reported clinical contraindications to either surgical procedure in our analyses did not change the conclusions in this study. Also, although our study was population based, we had to exclude all Asian women and US-born women younger than age 50 years with invasive carcinoma in Los Angeles because of involvement in other studies. Thus, our findings may not be generalizable to these groups. The study was necessarily retrospective in design. Patient recall of their encounters with clinicians may vary because of the passage of time. However, the average time from treatment to completion of the questionnaire was 6 months (range, 1 to 14 months), and there was no association between time from the diagnosis date to the questionnaire completion date and the findings described in this study.

The findings of this study have important implications for patient care and policy. Regional variations in surgical treatment patterns have resulted in lingering concerns that surgeons continue to overtreat women with breast cancer despite clinical guidelines that favor BCS.[1,2] Furthermore, Wennberg[13] has argued that the high variation in patterns of surgical treatment for breast cancer is "evidence [of the] failure to involve women in making decisions about which surgery they prefer." An Institute of Medicine report on quality of cancer care suggested that "persistent widespread regional variation in the performance of BCS would appear to indicate that many women are not being offered a choice [between surgical procedures]."[15] Our findings, however, contradict these arguments because they suggest that most women perceived that they had control over the decision-making process, and many of these women seemed to have preferred and received mastectomy. Thus, regional variation may be a result of variations in patient preferences for mastectomy rather than lack of involvement in decision making. In addition, our results also suggest that increasing patient involvement may actually increase the rate of mastectomy.

Efforts to increase patient involvement in treatment decisions are laudable. Patient involvement in treatment decisions has been promoted on ethical grounds alone[19,35,36] and has been shown to improve outcomes such as decision conflict and patient satisfaction.[37,38] However, there are many challenges to shared decision making with patients. The diagnosis of cancer is a stressful experience for most patients. They and their families must make many treatment decisions with limited knowledge and major consequences over a short period of time. Most of these decisions are made with clinicians and staff they have met for the first time under difficult circumstances. Treatment decision making in oncology is complicated. Increasingly, patients may look to clinicians to navigate these uncertain waters because they may not have the desire or expectation to control or share in all treatment decisions. Addressing variations in patient preferences for control or involvement in clinical decisions is one of the great challenges in clinical medicine today.

Our findings also suggest that focusing on BCS treatment rates alone as a measure of quality of care is problematic for several reasons. First, there is no known ideal rate of BCS that can be used as a performance or quality indicator.[25] Second, focusing on utilization alone reinforces a blanket assertion that BCS is the more progressive and appropriate treatment.[15,16] Overemphasizing BCS as the right option may be fueling the one-sided presentation of surgical treatment options (focusing on BCS) that many women reported in our study. This may lead to lower quality of life if women are less satisfied with the decision-making process or regretful about their choice of mastectomy.[39] Indeed, focusing on rates alone may obscure more important outcome measures, such as patient satisfaction and health-related quality of life, which are more difficult to measure.[16] Current legislation mandating that surgeons inform patients of all options for definitive surgical treatment was motivated by concerns that many women were not being adequately informed about BCS. Ironically, our findings suggest that many women are now not being adequately informed about the option of mastectomy. This may be because some surgeons are convinced that mastectomy is no longer clinically indicated for some women with early-stage disease without contraindication to BCS or that some patients do not desire a full explanation of all surgical options. Additional research is required to examine the interplay between patient and clinician perspectives about the treatment decision process and the influence of provider and organizational characteristics.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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