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Patient Reactions to Surgeon Recommendations About Contralateral Prophylactic Mastectomy for Treatment of Breast Cancer

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IMPORTANCE Guidelines assert that contralateral prophylactic mastectomy (CPM) should be discouraged in patients without an elevated risk for a second primary breast cancer. However, little is known about the impact of surgeons discouraging CPM on patient care satisfaction or decisions to seek treatment from another clinician.

OBJECTIVE To examine the association between patient report of first-surgeon recommendation against CPM and the extent of discussion about it with 3 outcomes: patient satisfaction with surgery decisions, receipt of a second opinion, and receipt of surgery by a second surgeon.

DESIGN, SETTING, AND PARTICIPANTS This population-based survey study was conducted in Georgia and California. We identified 3880 women with stages 0 to II breast cancer treated in 2013-2014 through the Surveillance, Epidemiology, and End Results registries of Georgia and Los Angeles County. Surveys were sent approximately 2 months after surgery (71% response rate, n = 2578). In this analysis conducted from February to May 2016, we included patients with unilateral breast cancer who considered CPM (n = 1140). Patients were selected between July 2013 and September 2014.

MAIN OUTCOMES AND MEASURES We examined report of surgeon recommendations, level of discussion about CPM, satisfaction with surgical decision making, receipt of second surgical opinion, and surgery from a second surgeon.

RESULTS The mean (SD) age of patients included in this study was 56 (10.6) years. About one-quarter of patients (26.7%; n = 304) reported that their first surgeon recommended against CPM and 30.1% (n = 343) reported no substantial discussion about CPM. Dissatisfaction with surgery decision was uncommon (7.6%; n = 130), controlling for clinical and demographic characteristics. One-fifth of patients (20.6%; n = 304) had a second opinion about surgical options and 9.8% (n = 158) had surgery performed by a second surgeon. Dissatisfaction was very low (3.9%; n = 42) among patients who reported that their surgeon did not recommend against CPM but discussed it. Dissatisfaction was substantively higher for those whose surgeon recommended against CPM with no substantive discussion (14.5%; n = 37). Women who received a recommendation against CPM were not more likely to seek a second opinion (17.1% among patients with recommendation against CPM vs 15.1% of others; *P* = .52) nor to receive surgery by a second surgeon (7.9% among patients with recommendation against CPM vs 8.3% of others; *P* = .88).

CONCLUSIONS AND RELEVANCE Most patients are satisfied with surgical decision making. First-surgeon recommendation against CPM does not appear to substantively increase patient dissatisfaction, use of second opinions, or loss of the patient to a second surgeon.

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Supplemental content

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Rates of contralateral prophylactic mastectomy (CPM) in US women with unilateral breast cancer have increased, largely because of patients' desire for the procedure.[1] More patients consider CPM today because of greater awareness of the treatment option and psychological factors that motivate their preferences for the most extensive surgical treatment.[2] Current clinical guidelines suggest that CPM should be discouraged in patients who do not have elevated risk for a second primary breast cancer based on family history and results of genetic testing.[3,4] However, most women who undergo CPM after a diagnosis of breast cancer have an average risk for developing a second breast primary, and rates of contralateral breast cancer have been decreasing steadily owing to the increased use of adjuvant systemic therapy for early-stage disease.[5,6] The complex interaction between patient desires for the most extensive treatment and the surgeon's role in minimizing surgical morbidity is poorly understood. In particular, little is known regarding the impact of a surgeon discouraging CPM and patient satisfaction with care or the decision to seek treatment with another surgeon. To address this knowledge gap, we examined patient reactions to recommendations regarding surgery options made by their first surgical consultant following a diagnosis of breast cancer by considering 3 outcomes: patient satisfaction with the surgery decision, receipt of a second surgical opinion, and whether a second surgeon performed the definitive surgery. We also examined the extent to which CPM was discussed and its association with patient appraisal of surgery decision making. We hypothesized that patient report of a first-surgeon recommendation against CPM may result in less-satisfied patients, more second opinions, and greater likelihood of receipt of surgery from a second surgeon.

Key Points

Question What is the response of patients to their first surgeon's recommendations against contralateral prophylactic mastectomy (CPM) with regard to decision satisfaction, receipt of a second opinion, or receipt of surgery from a second surgeon?

Findings In this population-based survey, one-quarter of patients reported that their surgeon recommended against CPM and one-third noted no substantial discussion about it. Women who received a recommendation against CPM were less satisfied with the surgery decision, but not more likely to seek a second opinion or to receive surgery by a second surgeon.

Meaning First-surgeon recommendation against CPM does not appear to substantively increase patient dissatisfaction, use of second opinions, or loss of the patient to a second surgeon.

Methods

Study Sample and Data Collection

After institutional review board approval from the University of Michigan, Emory University, and the University of Southern California, we selected women aged 20 to 79 years and diagnosed as having stages 0 to II breast cancer who were reported to the Surveillance, Epidemiology, and End Results (SEER) registries of Georgia and Los Angeles County. We received a waiver of written informed consent, as participation in the survey study (after receiving detailed information about the study, benefits and risks, and their rights as a participant) was considered adequate informed consent. Eligible patients were identified via initial surgical pathology reports from a list of definitive procedures (performed with intent of removing the entire tumor with clear margins). Patients were selected approximately 2 months after surgery and surveys were mailed on a monthly basis shortly after (mean [SD] diagnosis survey completion, 6 [2.8] months). To select participants with early-stage breast cancer, patients with stage III or IV disease, tumors greater than 5 cm, or 3 or more involved lymph nodes were excluded. Black, Asian, and Hispanic women were oversampled in Los Angeles using an approach we previously described.[7] Patients were selected between July 2013 and September 2014, with data analysis condicyed from February to May 2016. To encourage response, we provided a $20 cash incentive and used a modified Dillman method for patient recruitment,[8] including reminders to nonrespondents. All materials were sent in English. We also included Spanish-translated materials to all women with surnames suggesting Hispanic ethnicity.[7] Responses to the survey were merged with clinical data from SEER.

We selected 3880 women diagnosed as having early-stage breast cancer in 2013-2014 based on rapid reporting systems from the SEER registries; among them, 249 were later deemed ineligible owing to having a prior breast cancer diagnosis or stage III-IV disease; residing outside the SEER registry area; or being deceased, too ill/incompetent, or unable to complete a survey in Spanish or English. Of 3631 eligible women remaining, 1053 did not return a survey or refused to participate. Of 2578 patients who responded (71%), 110 patients with bilateral disease were excluded. Additionally, we excluded 1328 patients who reported no consideration of CPM, leaving 1140 (mean [SD] age, 56 [10.6] years; 46.2% of those with unilateral disease) for the analytic sample (eFigure in the Supplement).

Questionnaire Design and Content

Questionnaire content was developed based on a conceptual framework,[9-12] research questions, and hypotheses. We developed measures drawing from the literature and our prior research. We used standard techniques to assess content validity, including systematic review by design experts, cognitive pretesting with patients, and pilot studies in selected internet and clinic populations.

Measures

There were 3 primary dependent variables in this study. Dissatisfaction with the surgery decision was constructed from the Patient Satisfaction With the Surgery Decision Scale validated in prior studies (continuous measure range from 1 to 5 calculated by averaging a 5-item scale; Likert response categories 1 to 5 from not at all to very satisfied).[13,14] This was created as a binary outcome (satisfied/dissatisfied) as this had more clinically meaningful interpretation. A cutoff

below 3 indicated dissatisfaction. We performed sensitivity analyses evaluating a continuous variable and varying the cutoff for the binary specification. The 2 other dependent variables were whether the patient reported receiving a second opinion about the surgery decision (yes/no) and whether they had their breast cancer surgery by a second surgeon (yes/no).

There were 2 primary independent variables. Patient report of first-surgeon recommendation about CPM was ascertained by asking patients, "How strongly did the first surgeon you consulted recommend having a mastectomy on both breasts?" The 5 response categories were strongly/weakly recommended for CPM, left up to the patient, or strongly/weakly recommended against CPM. We created a binary variable a priori that indicated that the surgeon recommended against CPM vs recommended CPM or it was left up to the patient. A level of discussion about CPM during treatment deliberation was measured using a 5-item assessment of whether surgeons discussed the specific benefits and risks of CPM with regard to (1) survival, (2) recurrence of treated cancer, (3) occurrence of new contralateral cancer, (4) cosmetic outcomes, and (5) recovery from surgery. This was also categorized as a binary outcome for clinical interpretability. We considered that CPM was not substantively discussed if patients reported that it was not discussed for any of the 5 items. Sensitivity analyses specified a priori were performed using an ordinal approach (no tradeoffs discussed, 3 discussed, or all discussed). Additional covariates included age, marital status, education, insurance, race/ethnicity, and an indicator of elevated risk for second primary breast cancer vs average risk (based on a detailed assessment of family cancer history and genetic testing results) all derived from the patient survey. We also included geographic site and stage derived from SEER clinical information.

Statistical Analysis

First, we examined the characteristics of the total population followed by the distribution of key outcomes and covariates for women who reported any consideration of CPM. We then conducted logistic regression to examine the association between the binary variable of first surgeon recommended against CPM and sociodemographic factors (marital status, age, education, race/ethnicity, and paid work at time of diagnosis), risk for second primary, and geographic site. Finally, we calculated adjusted proportions of the 3 outcome variables by surgeon recommendation and the CPM discussion variable by creating separate logistic regression models for each of the outcomes and generating the marginal probabilities, averaging across the independent variables. All statistical analyses incorporate weights to account for differential probabilities of sample selection and survey nonresponse and to assure that the distributions of our sample resemble those of the target population.[15]

Multiple imputations of missing data[16] were used in all multivariable models to reduce potential for bias due to missing data and improve efficiency by taking full advantage of our data. Estimates and their variances from the multiple imputation results were combined according to the Rubin method.[17] Sensitivity analyses included respecifying the binary decision dissatisfaction variable as a continuous variable, testing different cutoffs, and limiting models to nonmissing data.

Results

The **Table** shows the characteristics and outcomes for the study sample. More than half of the patients (56.1%) were younger than age 60 years, 25.3% completed high school or less, and 44.1% were nonwhite. More than half (57.5%) of the study sample considered CPM strongly or very strongly (vs weakly or moderately). Ultimately, 40.5% underwent breast-conserving therapy, 22% unilateral mastectomy (41.4% of whom underwent breast reconstruction), and 38.2% CPM (76.7% of whom underwent breast reconstruction).

About one-quarter (26.7%) of the total study patients reported that their first surgeon recommended against CPM and 32.3% reported no substantial discussion about CPM. Dissatisfaction with the surgery decision was uncommon (7.6%). One-fifth of patients (20.6%) had a second opinion about surgical options and 9.8% had surgery performed by a second surgeon. Dissatisfaction with the surgery decision was higher for women who reported that their surgeon recommended against CPM (12.8% vs 6.5%; $P < .01$) or for whom CPM was not discussed (13.5% vs 6.0%; $P < .01$). Dissatisfaction was also higher among women who were of nonwhite race, at higher risk for developing a second primary cancer, had a higher-stage cancer, or who resided in Los Angeles County. Second opinions were more common among patients who were younger, more educated, did not have Medicare, and who worked for pay. Receipt of surgery by a second surgeon was more common among patients who worked for pay or who resided in Los Angeles County.

First-surgeon recommendation against CPM was highly associated with low rates of receipt of CPM (6.1% vs 57.5% of those with no recommendation against CPM; $P < .01$). **Figure 1** shows correlates of recommendations against CPM. Recommendation against CPM was only associated with geographic site: surgeons in Los Angeles County were more likely to recommend against CPM. There was no significant association with marital status, age, education, insurance, race/ethnicity, working for pay at time of diagnosis, or risk for recurrence.

Figure 2 shows the adjusted proportion of patients dissatisfied with the surgery decision by surgeon recommendation and extent of discussion about CPM controlling for other factors. Dissatisfaction was very low (3.9%) among patients who reported that their surgeon did not recommend against CPM but discussed it. Dissatisfaction with the surgery decision was somewhat higher for women whose surgeon did not recommend against CPM but did not substantively discuss it (7.7%; n = 267) or recommended against with discussion (7.6%; n = 244). Dissatisfaction was highest for those whose surgeon recommended against CPM with no substantive discussion (14.5%; n = 188), but this group represented only about 13% of patients in the sample. Dissatisfaction differed significantly across the 4 groups ($P < .01$).

Table. Sample Characteristics

Characteristic	No. (%)
Surgeon recommendation	
Not against CPM	767 (67.3)
Against CPM	304 (26.7)
Missing	69 (6.0)
Discussion of CPM	
Discussed	720 (63.1)
Not discussed	343 (30.1)
Missing	77 (6.8)
Age group, y	
<50	264 (23.1)
50-59	374 (32.8)
60-69	326 (28.6)
≥70	174 (15.3)
Missing	2 (0.2)
Education	
≤High school	288 (25.3)
Some college/technical school	360 (31.6)
College graduate	477 (41.8)
Missing	15 (1.3)
Insurance	
Private	700 (61.4)
Medicaid	152 (13.3)
Medicare	239 (21.0)
None	8 (0.7)
Missing	41 (3.6)
Race/ethnicity	
White	613 (53.7)
Black	182 (16.0)
Hispanic	210 (18.4)
Asian	92 (8.1)
Missing	43 (3.8)
Marital status	
Not married	396 (34.7)
Married/partner	728 (63.9)
Missing	16 (1.4)
Employment status before diagnosis	
Not working for pay	255 (22.4)
Working for pay	748 (65.6)
Missing	137 (12.0)
Risk for recurrence	
Not high risk	455 (39.9)
High risk	685 (60.1)
Cancer stage	
0	184 (16.1)
I	630 (55.3)
II	326 (28.6)
Consideration of CPM	
Weak/moderate	462 (40.5)
Strong/very strong	625 (54.9)
Missing	53 (4.6)
Site	
Georgia	642 (56.3)
Los Angeles County	498 (43.7)
Ultimate treatment	
Breast-conserving surgery	447 (39.2)
Unilateral mastectomy	251 (22.0)
Bilateral mastectomy	435 (38.2)
Missing	7 (0.6)

Abbreviation: CPM, contralateral prophylactic mastectomy.

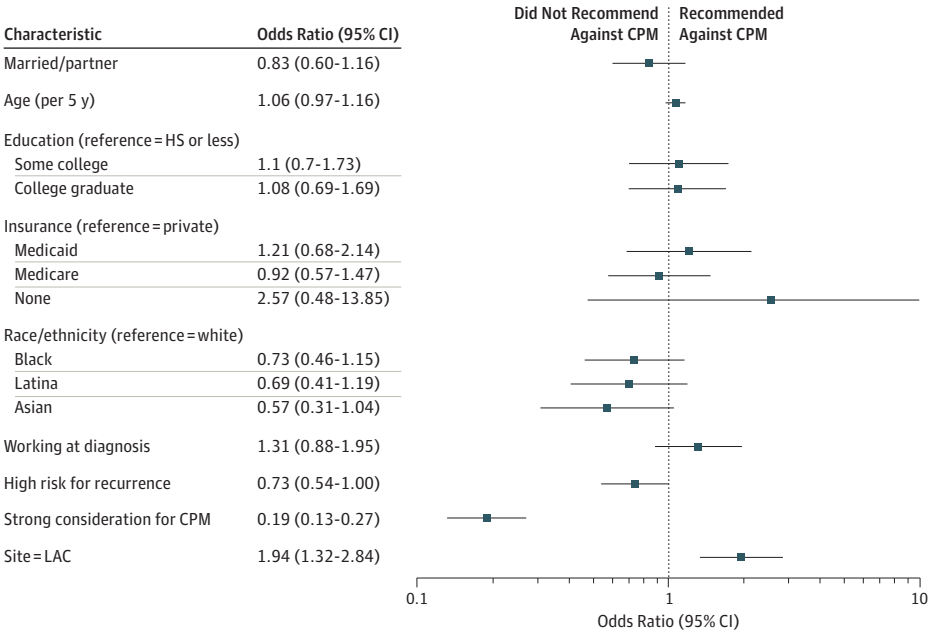
Figure 3 shows the proportion of patients who sought a second opinion or received surgery by a second surgeon by first-surgeon CPM recommendation categories adjusted for other factors. Women who received a recommendation against CPM were not more likely to seek a second opinion (17.1% among patients with recommendation against CPM vs 15.0% of others; $P = .52$) nor to receive surgery by a second surgeon (7.9% in both recommendation groups; $P = .88$).

Hosmer-Lemeshow tests did not indicate significant lack of fit; the χ^2 statistics from these tests ranged from 3.4 to 9.9 across models and imputations (range, $P = .27$ to .90). Alternative specifications of the decision satisfaction measure looking at different cutoffs or treating it as a continuous variable showed no significant differences in model results. No significant interactions were found between any of the independent variables.

Discussion

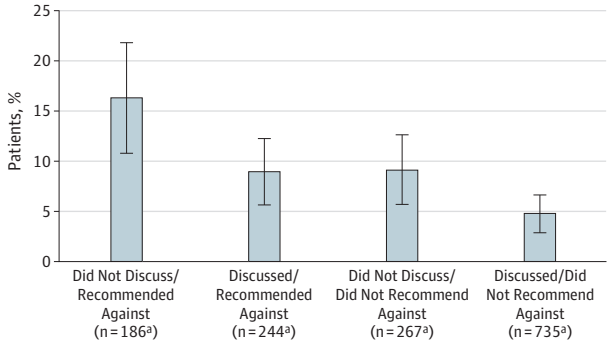
In this large diverse population-based sample of patients newly diagnosed as having breast cancer, about half with unilateral disease considered CPM. Among these patients, about one-quarter reported that their first surgeon recommended against CPM, and one-third reported that CPM was not substantively discussed with their surgeon(s). There were no significant differences in the likelihood of CPM recommendation by sociodemographic factors except for geographic location. Geographic variation in surgeon recommendation may suggest differences in practice network factors with regard to how surgeons approach communication about CPM. Both surgeon recommendation against CPM and lack of a substantive discussion were associated with patient dissatisfaction with the surgery decision. The additive effect was modest: nearly 15% of patients were dissatisfied with the surgery decision process when a first surgeon recommended against CPM but there was no substantive discussion about it (vs 4% in patients who did not receive a recommendation against CPM but had a discussion about it). However, only about 15% of patients reported this circumstance. Second opinions about surgery were not common (15.7%) and surgery performed by a second surgeon even less so (8.1%). First-surgeon recommendation against CPM was not associated with the frequency of second

Figure 1. Correlates of Surgeon Recommendation Against Contralateral Prophylactic Mastectomy



Odds ratios (95% CIs) from a logistic regression model using multiple imputation for missing data and weights for differing probabilities of sample selection and nonresponse. CPM indicates contralateral prophylactic mastectomy; HS, high school; and LAC, Los Angeles County.

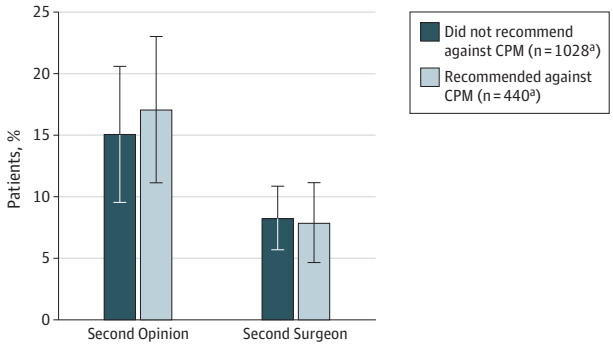
Figure 2. Dissatisfaction With Surgical Decision by Surgeon Recommendation and Extent of Discussion About Contralateral Prophylactic Mastectomy



Predicted probabilities of surgical decision dissatisfaction. Rates are marginal predictions derived from a multivariable logistic model, averaging over marital status, education, insurance, race/ethnicity, employment, cancer stage, risk for recurrence, site, and consideration for contralateral prophylactic mastectomy. The error bars indicate 95% CIs.

[a] Weighted to account for oversampled groups in the design and nonresponse.

Figure 3. Receipt of Second Opinion or Surgery by Second Surgeon by Surgeon Recommendation



Predicted probabilities of second opinion and surgery by second surgeon. Rates are marginal predictions derived from a multivariable logistic model, averaging over marital status, education, insurance, race/ethnicity, employment, cancer stage, risk for recurrence, site, and consideration for contralateral prophylactic mastectomy (CPM). The error bars indicate 95% CIs.

[a] Weighted to account for oversampled groups in the design and nonresponse.

opinion or patient receipt of surgery by a second surgeon. Furthermore, there were no substantive sociodemographic or clinical correlates of second opinions or receipt of surgery from a second surgeon.

To our knowledge, this is the first study that examined the nature of physician-patient discussions about CPM and patient reactions to surgeon recommendations regarding elective CPM. Published studies have documented the growth in receipt of CPM in the United States over the last decade,[6,18-21] and a few have addressed patient factors driving preferences for more extensive surgery.[2] Other studies have examined surgeon perspectives but they have been limited by small samples, low response rates, or non-US practice settings.[22,23]

Strengths and Limitations

Some aspects of our study methods merit comment. The study was a large population-based survey in a diverse sample with a high survey response rate. We used weights and multiple imputation techniques to reduce nonresponse bias. Patient report of treatment deliberation and experiences were ascertained shortly after surgery. We were conservative with regard

to specification of the main measures. For example, patients had to indicate that none of the 5 CPM treatment tradeoffs were discussed to be characterized as not having a substantive discussion. Furthermore, we performed sensitivity analyses to assure that main findings based on a priori decisions were robust for different specifications of key variables and different approaches to analyses. However, there were some limitations. Surgeon communication was reported by patients and thus may differ from a report from their surgeon. The population-based survey was necessarily retrospective. In particular, we evaluated strength of consideration of CPM after treatment, which may have been influenced by deliberations and the surgical treatment ultimately performed. We had little information about potential barriers to discussion or care by second surgeons, which may have affected our findings. Finally, results are limited to 2 large regions of the United States.

Conclusions

Surgeons face a growing need to address patient interest in CPM for treatment of breast cancer. Communicating with patients about CPM is difficult because patient preferences are motivated by complex intuitive and affective reactions that may be difficult to elicit and address in a visit where a myriad of treatment options and potential outcomes need to be discussed. Under these circumstances, surgeons may not feel compelled to initiate a discussion of CPM or proactively make recommendations in women with no medical indication for the procedure in an effort to optimally facilitate patient participation in a complicated treatment decision process. Our findings are largely reassuring in that most patients are satisfied with surgical decision making and that first-surgeon recommendation against CPM does not appear to substantively increase patient dissatisfaction or increase use of second opinions or loss of the patient to a second surgeon. However, the proportion of patients reporting a recommendation against CPM by their first surgeon was modest. The consequences of a greater number of surgeons advising against CPM are unknown, especially in women who strongly desire the procedure. For patients who remain uncertain about the benefits of CPM, a second opinion may be an appropriate source of additional information. Research is needed to develop and evaluate both decision tools for patients and training opportunities for surgeons that can facilitate these very important clinical encounters concerning challenging treatment decision issues.

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Author Contributions: Dr Katz had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.
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