Original Investigation

Access to Breast Reconstruction After Mastectomy and Patient Perspectives on Reconstruction Decision Making

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IMPORTANCE Most women undergoing mastectomy for breast cancer do not undergo breast reconstruction.

OBJECTIVE To examine correlates of breast reconstruction after mastectomy and to determine if a significant unmet need for reconstruction exists.

DESIGN, SETTING, AND PARTICIPANTS We used Surveillance, Epidemiology, and End Results registries from Los Angeles, California, and Detroit, Michigan, for rapid case ascertainment to identify a sample of women aged 20 to 79 years diagnosed as having ductal carcinoma in situ or stages I to III invasive breast cancer. Black and Latina women were oversampled to ensure adequate representation of racial/ethnic minorities. Eligible participants were able to complete a survey in English or Spanish. Of 3252 women sent the initial survey a median of 9 months after diagnosis, 2290 completed it. Those who remained disease free were surveyed 4 years later to determine the frequency of immediate and delayed reconstruction and patient attitudes toward the procedure; 1536 completed the follow-up survey. The 485 who remained disease free at follow-up underwent analysis.

EXPOSURES Disease-free survival of breast cancer.

MAIN OUTCOMES AND MEASURES Breast reconstruction at any time after mastectomy and patient satisfaction with different aspects of the reconstruction decision-making process.

RESULTS Response rates in the initial and follow-up surveys were 73.1% and 67.7%, respectively (overall, 49.4%). Of 485 patients reporting mastectomy at the initial survey and remaining disease free, 24.8% underwent immediate and 16.8% underwent delayed reconstruction (total, 41.6%). Factors significantly associated with not undergoing reconstruction were black race (adjusted odds ratio [AOR], 2.16 [95% CI, 1.11-4.20]; \( P = .004 \)), lower educational level (AOR, 4.49 [95% CI, 2.31-8.72]; \( P < .001 \)), increased age (AOR in 10-year increments, 2.53 [95% CI, 1.77-3.61]; \( P < .001 \)), major comorbidity (AOR, 2.27 [95% CI, 1.01-5.11]; \( P = .048 \)), and chemotherapy (AOR, 1.82 [95% CI, 0.99-3.31]; \( P = .05 \)). Only 13.3% of women were dissatisfied with the reconstruction decision-making process, but dissatisfaction was higher among nonwhite patients in the sample (AOR, 2.87 [95% CI, 1.27-6.51]; \( P = .03 \)). The most common patient-reported reasons for not having reconstruction were the desire to avoid additional surgery (48.5%) and the belief that it was not important (33.8%), but 36.3% expressed fear of implants. Reasons for avoiding reconstruction and systems barriers to care varied by race; barriers were more common among nonwhite participants. Residual demand for reconstruction at 4 years was low, with only 30 of 263 who did not undergo reconstruction still considering the procedure.

CONCLUSIONS AND RELEVANCE Reconstruction rates largely reflect patient demand; most patients are satisfied with the decision-making process about reconstruction. Specific approaches are needed to address lingering patient-level and system factors with a negative effect on reconstruction among minority women.

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Universal coverage for postmastectomy breast reconstruction was mandated after the enactment of the Women’s Health and Cancer Rights Act in the United States in 1998. Despite guaranteed insurance coverage, most women undergoing mastectomy for breast cancer do not undergo breast reconstruction, with rates of reconstruction ranging from 25% to 35% in population-based studies of women treated from 2003 through 2007. Even among women treated in National Cancer Institute–designated cancer centers participating in the National Comprehensive Cancer Network, slightly more than 50% of those undergoing mastectomy underwent reconstruction. Variations in rates of reconstruction have been associated with age, insurance status, ethnicity, and supply of reconstructive surgeons. This variation, coupled with evidence of significant between-surgeon variation in discussion of reconstruction and rates of mastectomy and breast reconstruction suggests that patients’ needs for reconstruction may not be addressed fully. These concerns resulted in the passage of a New York State law in 2010 mandating that surgeons discuss the availability of breast reconstruction with patients before breast cancer treatment, provide information about insurance coverage, and refer them to a hospital where reconstruction is available if necessary. However, little is known about patient perceptions regarding reconstruction, and whether a significant unmet need for breast reconstruction exists remains unknown. In addition, most studies that have examined reconstruction do not include patients who underwent the surgical procedure later (delayed reconstruction). A previous study reported that delayed reconstruction was infrequent in a population-based sample of women diagnosed as having breast cancer in 2002 and found that only 59% of patients in that study who did not undergo reconstruction believed that they were adequately informed about the procedure. The purpose of this study was to examine the rates of immediate and delayed breast reconstruction and correlates of their use in a diverse, population-based sample treated in a more recent period to determine whether significant gaps in awareness regarding breast reconstruction persist. In addition, we sought to examine patient attitudes toward reconstruction and identify whether a significant unmet need for reconstruction after completion of cancer treatment exists.

Methods

Study Population and Data Collection

Women in the metropolitan areas of Los Angeles, California, and Detroit, Michigan, who were aged 20 to 79 years; were diagnosed as having ductal carcinoma in situ or invasive breast cancer from June 1, 2005, through February 28, 2007; and were reported to the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program registries in both regions were eligible for initial sample selection. Patients were excluded if they had stage IV breast cancer, died before the initial survey, or could not complete the initial questionnaire in English or Spanish. Asian women in Los Angeles also were excluded because of enrollment in other studies. Latina (in Los Angeles) and black (in Los Angeles and Detroit) patients were oversampled to ensure sufficient representation of racial/ethnic minorities.

Eligible patients were identified via rapid case ascertainment as they were reported monthly to the collaborating SEER registries. Physicians were notified of our intent to contact patients, followed by a patient mailing consisting of a letter, survey materials, and a $10 cash gift to eligible study participants. All materials were sent in English and Spanish to those with Spanish surnames. Patients were initially interviewed at a mean of 9 months after diagnosis (mean completion window, 9 [range, 5-14] months). A follow-up survey was sent to those who completed the baseline survey approximately 4 years after diagnosis (mean completion window, 50 [range, 36-65] months). The Dillman survey method was used for both surveys to encourage response.

The Figure shows the decay in the sample from the initial accrual of patients through the selection of the sample for the analysis in this study. Of 3252 patients initially identified and sent a baseline survey, 2290 (73.1%) completed that survey; and 1536 patients (67.7%) completed the follow-up survey. The overall response rate was 49.4% (1536 of 3111 [3252 initially identified patients minus 119 who were excluded and 22 whose baseline survey could not be merged with SEER data]). The analytic sample for this study consists of the 485 patients who reported undergoing mastectomy at the initial survey, completed the follow-up survey, and indicated that they did not have a recurrence of breast cancer. The study protocol was approved by the institutional review boards of the University of Michigan in Ann Arbor, University of Southern California, and Wayne State University, Detroit. Informed consent was waived because completion of the survey was believed to indicate consent.

Figure. Study Flow Diagram

| 3252 Patients with breast cancer identified and sent baseline survey |
| 119 Excluded |
| 59 Were too ill |
| 23 Denied having cancer |
| 20 Physicians refused contact with patient |
| 17 Spoke neither English nor Spanish |
| 2290 Completed a baseline survey (response rate, 73.3%) |
| 22 Could not be merged with SEER data |
| 1536 Completed a follow-up survey about 4 y after diagnosis (response rate, 68%) |
| 485 Final analytic sample |
| 1051 Analytic exclusions |
| 1024 Had undergone no mastectomy at initial survey |
| 27 Had recurrence |

SEER indicates Surveillance, Epidemiology, and End Results registry of the National Cancer Institute.
Measures
A primary outcome of interest was a binary variable that indicated whether or not a patient underwent breast reconstruction at any time since the mastectomy, obtained from both surveys. The second outcome of interest was patient satisfaction with different aspects of the reconstruction decision-making process, obtained from the follow-up survey. Patients were asked to agree/disagree with statements regarding their satisfaction with the following aspects of the decision-making process: (1) being satisfied with the decision about whether to have reconstruction; (2) not regretting the choice they made regarding whether to have breast reconstruction; and (3) being satisfied with the information given about the issues important to breast reconstruction. The response category format was a Likert scale that ranged from 1 (strongly disagree) to 5 (strongly agree). The items were recoded to obtain congruent valence, and a mean was calculated to make a scale. We dichotomized the scale score as low satisfaction (<3) or higher satisfaction (≥3). In addition, we examined the reasons why patients did not undergo breast reconstruction or delayed reconstruction across the following 2 dimensions: (1) patient factors, such as their attitudes toward reconstruction (ie, worry, too much time off work or away from family) or clinical reasons; and (2) systems factors. Patients were asked to what extent each reason contributed to their decision, ranging from 1 (“not at all”) to 5 (“a lot”) using a Likert scale.

The independent variables considered in this study included patient demographics, patient clinical/treatment factors, and site (Detroit vs Los Angeles). Patient demographics included age, educational level, race/ethnicity, partner status, income, insurance types, and smoking status. Patient clinical factors included cancer stage, presence of key medical comorbidities (ie, chronic obstructive pulmonary disease, heart disease, diabetes mellitus, or stroke), and breast size. Treatment factors included chemotherapy, radiotherapy, and timing of reconstruction (delayed or immediate reconstruction after mastectomy). All these variables were self-reported except cancer stage. We used the American Joint Committee on Cancer staging system to classify cancer stage, which was obtained from the SEER registry.

Statistical Analysis
We first conducted an analysis comparing key baseline categorical variables between responders (those who completed the baseline and follow-up surveys) and nonresponders using χ² tests. We then calculated summary statistics on our sample population using percentages for categorical variables and means and standard deviations for continuous variables. Logistic regression was used to assess the odds of patients not undergoing reconstruction after mastectomy. The independent variables for this model included age, partner status, educational level, race/ethnicity, income, insurance types, comorbidities, prediagnosis brassiere cup size, cancer stage, radiotherapy, chemotherapy, contralateral prophylactic mastectomy, and SEER site. Similarly, we used logistic regression to model the odds of being dissatisfied with the decision-making process. The independent variables for this model included the status of reconstruction (yes vs no), age, educational level, race/ethnicity, marriage/partner status, income, insurance type, cancer stage, and SEER site. To achieve parsimony of the regression models, we used a backward variable selection method to eliminate the variables that did not reach the statistical significance level of .10. Finally, we described the distribution of responses on a list of reasons why women did not receive reconstruction or delayed the procedure. This list was based on the percentages of patients who reported that a given issue contributed to their decision to omit or delay reconstruction (“quite a bit,” “a lot,” “somewhat,” and “not at all”). We examined the difference in these percentages across racial/ethnic groups using Mantel-Haenszel tests.

All the descriptive and regression analyses described above were weighted using survey procedures (eg, PROC SURVEYLOGISTIC [SAS Institute] for logistic regression) to account for differential probabilities of sample selection and nonresponse, which made our statistical inference more representative of the population. We created an analytic weight that accounted for the initial sampling design (oversampling of black and Latina patients and disproportionate selection across geographic sites) and differential nonresponse in the 2 survey waves. All analyses used commercially available statistical software (SAS, version 9.2; SAS Institute).

Results
An analysis of sampled patients comparing nonrespondents with respondents who completed the initial and the follow-up surveys showed no significant differences by age at diagnosis. However, compared with respondents, nonrespondents to the follow-up survey were more likely to be black (35.2% vs 26.7%; P < .001) or Latina (17.2% vs 13.3%; P = .002). Patients who had undergone any breast reconstruction were less likely to have undergone mastectomy (54.9% vs 37.8%; P < .001), and more likely to have undergone mastectomy (37.5% vs 30.8%; P < .001).

The characteristics of the patient population are summarized in Table 1 and Table 2. The mean age was 55.8 years; 42.2% had no more than a high school education, and 64.3% had stage I or II breast cancer. Postmastectomy radiotherapy was reported by 33.0%, and 11.6% underwent a contralateral prophylactic mastectomy. Overall, 41.6% of the 485 patients treated with mastectomy who remained disease free had breast reconstruction; 146 of the procedures (24.8%) were performed at the time of mastectomy, and 76 (16.8%) were delayed. The most common type of reconstruction used implants or tissue expanders (61.9% of those undergoing reconstruction). A multivariable regression analysis of factors associated with undergoing any mastectomy reconstruction is shown in Table 3. Black patients, those with more than a high school education, those without private insurance, those with any major comorbidity, older women, and those residing in Los Angeles County were significantly less likely to undergo reconstruction than their counterparts. Patients who received chemotherapy were also significantly less likely to undergo reconstruction.

Most women reported being satisfied with the decision-making process regarding reconstruction. The mean satisfaction score was 3.9 (SE, 0.05) on a 5-point Likert scale. About
Table 4 shows correlates of dissatisfaction with the decision-making process; dissatisfaction was associated with being black or Latina (P = .03) but not with lower income or educational levels.

Table 5 for the 263 women treated with mastectomy alone. Common reasons among women of all racial/ethnic groups were the desire to avoid additional surgery (48.5%) or the feeling that reconstruction was not important (33.8%). However, ethnic minority groups were less likely to report the desire to avoid additional surgery (70.0% for non-black, non-Latina patients vs 39.7% and 34.1% for black and Latina patients, respectively; P < .001) or that reconstruction was not important (42.4% for nonblack, non-Latina patients vs 21.6% and 31.3% for black and Latina patients, respectively; P = .04). Fear of implants (36.3%) was another commonly reported reason for not undergoing reconstruction. Concerns about interference with the detection of cancer and lack of awareness of the availability of reconstruction were cited by 23.9% and 18.1% of the sample, respectively. We found significant racial/ethnic gradients for some of the other reasons given for not undergoing reconstruction. More Latina patients reported concerns about interference with cancer detection or complications of the procedure and not being able to take time off from work or family. More black and Latina patients reported the systems barrier of having no insurance coverage.

Most of the 76 patients who underwent delayed breast reconstruction reported treatment-related reasons for the delay, including the need to focus on cancer treatment (68.7%) or the need to accommodate chemotherapy (50.7%) or radiotherapy (26.3%) (Table 6). Fewer than 15% indicated that they were unaware of the option of breast reconstruction at the time of their breast cancer surgery or that they had problems with insurance. We found little residual demand for breast reconstruction among women who had not undergone the procedure by 4 years after diagnosis; only 30 of the 263 respondents (11.4%) who had not undergone reconstruction indicated they were still considering the procedure.

13.3% of women reported being dissatisfied with the decision-making process (score, <3). Table 4 shows correlates of dissatisfaction with the reconstruction decision-making process; dissatisfaction was associated with being black or Latina (P = .03) but not with lower income or educational levels.

Table 1. Demographic Characteristics of 485 Participants With Breast Cancer Who Underwent Mastectomy

Table 2. Clinical Characteristics of 485 Participants With Breast Cancer Who Underwent Mastectomy
The rate of reconstruction was 41.6% (24.8% immediate and 16.8% delayed). These findings are consistent with the 25% to 29% rate observed in statewide data from California, but somewhat higher than what was seen in a series from the M.D. Anderson Cancer Center, in which 8% of women underwent delayed reconstruction 15 to 27 months after mastectomy, but suggests that most women desiring breast reconstruction have access to immediate breast reconstruction. Although patients who underwent mastectomy alone were less likely than mastectomy with reconstruction to forgo reconstruction and results in a senescent breast mound. In contrast, mastectomy with reconstruction often requires additional surgical procedures, and the reconstructed breast lacks normal sensation, making breast-conserving surgery the preferred choice for some women desiring to maintain a breast. Greenberg et al have demonstrated a strong inverse correlation between institutional rates of breast-conserving surgery and mastectomy with reconstruction (r = −0.80; P = .02) but no correlation between institutional rates of mastectomy alone and breast-conserving surgery or between mastectomy alone and mastectomy plus reconstruction.

We found that 16.8% of mastectomy-treated patients delayed reconstruction. This finding from a population study is somewhat higher than what was seen in a series from the M.D. Anderson Cancer Center, in which 8% of women underwent delayed reconstruction 15 to 27 months after mastectomy, but suggests that most women desiring breast reconstruction have access to immediate breast reconstruction. Patient report of reasons for delaying reconstruction clearly showed that coordinating treatment delivery was the major factor in the decision to forgo reconstruction in our study population. Another reassuring finding from this study is that 4 years after diagnosis, only 30 of the 263 patients (11.4%) who had not undergone reconstruction were still considering it.

Our results suggest that some barriers to breast reconstruction linger. Black patients were less likely than non-black, non-Latina patients to undergo reconstruction. In addition, patients without private insurance plans were less likely to undergo reconstruction. Patient-reported reasons for not undergoing reconstruction suggested patient knowledge- and attitude-related barriers and systems issues. Almost one-fifth of patients' feelings that reconstruction was not important and patients' desires to avoid additional surgery are the major factors responsible for low rates of reconstruction. Although feeling that reconstruction is not important may seem counterintuitive, breast-conserving surgery with radiotherapy is an alternative way to maintain a breast that is an option for most women with early-stage breast cancer, and involves a smaller surgical procedure with more rapid recovery than mastectomy with reconstruction, and results in a senescent breast mound. In contrast, mastectomy with reconstruction often requires additional surgical procedures, and the reconstructed breast lacks normal sensation, making breast-conserving surgery the preferred choice for some women desiring to maintain a breast. Greenberg et al have demonstrated a strong inverse correlation between institutional rates of breast-conserving surgery and mastectomy with reconstruction (r = −0.80; P = .02) but no correlation between institutional rates of mastectomy alone and breast-conserving surgery or between mastectomy alone and mastectomy plus reconstruction.

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women who did not undergo reconstruction reported a lack of knowledge regarding the procedure. Many women continue to report fear of implants as a reason for forgoing reconstruction, despite their proven safety. Nearly one-fourth of women who did not undergo reconstruction in our sample reported concern about potential interference with cancer detection as a decision factor despite the clinical evidence not countering may have varied over time. Finally, we noted substantial decay in the longitudinal sample, which may have introduced selection bias.

Conclusions

We found that women are largely satisfied with the process of making decisions about breast reconstruction and that stable rates of the procedure largely reflect patient demand. A minority of women delayed reconstruction within 4 years of cancer diagnosis, and delay was largely explained by relevant clinical and treatment-related factors. These findings suggest that legislative mandates to change the approach to patient education, such as a New York State law passed in 2010, are likely to be less effective than more ground-level practice initiatives, such as patient decision tools or encouragement of input from plastic surgeons at the time decisions about treatment are made. Our study suggests that room exists for improved education regarding the safety of breast implants and the effect of reconstruction on follow-up surveillance, information about which could be readily addressed through decision tools. Finally, development of specific approaches to address patient-level and systems factors with a negative effect on the use of reconstruction among minority women is needed.

ARTICLE INFORMATION
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Table 5. Reasons Given by Patients for Not Undergoing Reconstructiona

<table>
<thead>
<tr>
<th>Reason</th>
<th>% of Patientsb</th>
<th>Total</th>
<th>Nonblack, Non-Latina</th>
<th>Black</th>
<th>Latina</th>
<th>P Valuec</th>
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<td>Patient Factors</td>
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<tr>
<td>Did not want additional surgery</td>
<td>48.5</td>
<td>70.0</td>
<td>39.7</td>
<td>34.1</td>
<td>&lt;.001</td>
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<tr>
<td>Was not important</td>
<td>33.8</td>
<td>42.4</td>
<td>21.6</td>
<td>31.3</td>
<td>.04</td>
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<tr>
<td>Fear of implants</td>
<td>36.3</td>
<td>34.4</td>
<td>38.8</td>
<td>40.7</td>
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<tr>
<td>Concerned about interference with detection of recurrence</td>
<td>23.9</td>
<td>16.1</td>
<td>18.6</td>
<td>32.5</td>
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<tr>
<td>Concerned about possible complications</td>
<td>33.6</td>
<td>27.9</td>
<td>20.4</td>
<td>43.8</td>
<td>.02</td>
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<td>Could not take much time off work or from family</td>
<td>16.1</td>
<td>8.9</td>
<td>9.5</td>
<td>24.7</td>
<td>.02</td>
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<tr>
<td>Systems Factors</td>
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<tr>
<td>Did not know was an option</td>
<td>18.1</td>
<td>12.7</td>
<td>27.7</td>
<td>18.6</td>
<td>.51</td>
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<tr>
<td>Trouble finding surgeon</td>
<td>5.6</td>
<td>4.2</td>
<td>10.6</td>
<td>4.7</td>
<td>.51</td>
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<tr>
<td>No insurance coverage</td>
<td>11.8</td>
<td>2.2</td>
<td>23.7</td>
<td>18.6</td>
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<td>Surgeon did not take insurance</td>
<td>7.8</td>
<td>2.8</td>
<td>16.8</td>
<td>8.5</td>
<td>.09</td>
<td></td>
</tr>
</tbody>
</table>

a Includes 263 patients.
b Indicates percentage of patients who responded that the factor contributed “quite a bit” or “a lot” to the decision to not have breast reconstruction. Percentages are weighted to account for the sample design and nonresponse.
c Tests for differences in item response across race/ethnic groups.

Table 6. Reasons Given by Patients for Delay in Breast Reconstructiona

<table>
<thead>
<tr>
<th>Reason</th>
<th>% of Patientsb</th>
<th>Total</th>
<th>Nonblack, Non-Latina</th>
<th>Black</th>
<th>Latina</th>
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<tr>
<td>Needed radiotherapy</td>
<td>26.3</td>
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<td>Needed chemotherapy</td>
<td>50.7</td>
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<td>Focused on treating the cancer</td>
<td>68.7</td>
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<td>Patient Attitudes</td>
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<tr>
<td>Not sure wanted reconstruction</td>
<td>10.1</td>
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<tr>
<td>Too much time off work or from family</td>
<td>6.7</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Systems Factors</td>
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<tr>
<td>Did not know of the reconstruction option</td>
<td>14.3</td>
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</tr>
<tr>
<td>Trouble finding surgeon to perform reconstruction</td>
<td>0.0</td>
<td></td>
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<tr>
<td>Problems with initial breast surgery</td>
<td>8.1</td>
<td></td>
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<tr>
<td>No insurance coverage</td>
<td>10.3</td>
<td></td>
<td></td>
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</table>

a Includes the 76 patients who delayed breast reconstruction.
b Indicates percentage of patients who responded that the factor contributed “quite a bit” or “a lot” to the decision to delay breast reconstruction. Percentages are weighted to account for the sample design and nonresponse.
Author Contributions: Drs. Morrow and Katz had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors have read and approved the manuscript.

Study concept and design: Morrow, Adlerman, Katz.

Acquisition, analysis, or interpretation of data: Morrow, Li, Adlerman, Jaggi, Hamilton, Graff, Hawley.

Drafting of the manuscript: Morrow, Li, Adlerman, Katz.

Critical revision of the manuscript for important intellectual content: Morrow, Adlerman, Jaggi, Hamilton, Graff, Hawley.

Statistical analysis: Li, Adlerman.

Obtained funding: Hawley, Katz.

Administrative, technical, and material support: Morrow, Hamilton, Katz.

Study supervision: Adlerman, Katz.

Conflict of Interest Disclosures: None reported.

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REFERENCES


