

Can Women With Early-Stage Breast Cancer Make an Informed Decision for Mastectomy?

E. Dale Collins, Caroline P. Moore, Kate F. Clay, Stephen A. Kearing, Annette M. O'Connor, Hilary A. Llewellyn-Thomas, Richard J. Barth Jr, and Karen R. Sepucha

ABSTRACT

Purpose

The purpose of this study was to measure the degree to which informed women chose mastectomy, and to reveal their reasons for this choice.

Patients and Methods

This was a prospective cohort study of patients radiographically and pathologically eligible for either mastectomy or breast-conserving surgery (BCS; $n = 125$). Participants completed questionnaires at three time points: baseline, after viewing a decision aid, and after a surgical consultation. Questionnaires assessed clinical history, preference for participation in decision making, information comprehension, values, decisional conflict, and preferred treatment.

Results

Of 125 participants, 44 (35%) chose mastectomy. Most understood that BCS and mastectomy offer an equivalent survival benefit (98%) and that BCS has a slightly higher local recurrence risk (63%); most accurately identified the magnitude of ipsilateral local recurrence risk (91%). Values assigned to three treatment attributes/outcomes (“remove breast for peace of mind,” “avoid radiation,” and “keep breast”) clearly discriminated between patients choosing mastectomy or BCS. High decisional conflict scores improved after both the decision aid and surgical consultation.

Conclusion

Although conventional wisdom may view BCS as the preferred treatment, a notable proportion of well informed women choose mastectomy. Whereas prior studies have linked objective factors to treatment choice, this study reveals subjective preferences that underlie decision making. The systematic use of a decision aid before the surgical consultation may help women make informed, values-based decisions, while clearly reducing decisional conflict.

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INTRODUCTION

Breast-conserving surgery (BCS) is considered both the appropriate and preferred treatment for most women with early-stage invasive breast cancer.¹ Multiple studies have demonstrated no significant difference in overall survival among women undergoing mastectomy versus BCS plus radiation.²⁻⁵ Despite widespread acceptance of the prognostic equivalence of the two options, as well as a widespread assumption among medical professionals that BCS is the preferred treatment, mastectomies are still performed at high rates.^{1,6,7}

Factors predicting the choice of mastectomy among women eligible for BCS are diverse. Studies have shown that larger tumor size and nodal involvement are important clinical predictors.⁷ Nonclinical factors such as geography, socioeconomic status, age, and race are also important

variables.^{6,8-10} Some have hypothesized that patient preference may be trumped by the influence of others (eg, physicians or family members),¹¹⁻¹³ or that rates of mastectomy reflect inadequately informed patients.¹⁴ On the other hand, higher rates of mastectomy have been associated with greater patient involvement in the decision-making process.¹⁵

Given these apparently contradictory observations, the authors were interested in exploring this question: Can women with early-stage breast cancer make a high quality decision for mastectomy? There are two important conceptual points to note here. First, in preference-sensitive decision situations, “decision quality” refers to the extent to which the patient’s choice is (a) informed, (b) consistent with her personal attitudes (ie, her “values”) about the therapeutic options’ pros and cons, and (c) acted on.¹⁶ Therefore, high decision quality could be considered a laudable goal. Second, although laudable, this goal could be achieved at the cost of higher levels

From the Dartmouth Institute for Health Policy and Clinical Practice; Dartmouth Medical School, Hanover; Center for Shared Decision Making; Comprehensive Breast Program, Norris Cotton Cancer Center, Dartmouth-Hitchcock Medical Center, Lebanon, NH; Health Decision Research Unit, Massachusetts General Hospital, Boston, MA; and the School of Nursing, Faculty of Health Sciences, University of Ottawa, Ottawa, Ontario, Canada.

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Corresponding author: E. Dale Collins, MD, Dartmouth Hitchcock Medical Center, One Medical Center Dr, Lebanon, NH 03756; e-mail: e.dale.collins@hitchcock.org.

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of decisional conflict.¹⁷ “Decisional conflict” refers to the psychological discomfort a patient may experience as a result of the uncertainties inherent in making a preference-sensitive choice.

At our academic medical center, all newly diagnosed early-stage breast cancer patients receive standardized decision support (Fig 1¹⁶⁻¹⁹) before the surgical consultation. This provides an ideal setting in which to examine the decision-making processes of these patients in terms of the quality of their decision making and the level of decisional conflict they experience.

PATIENTS AND METHODS

Study Sample

The sample included women newly diagnosed with breast cancer treatable by either mastectomy or BCS and who had not yet met with a surgeon to discuss options between February 2005 and August 2007. Pregnant women and those with evidence of inflammatory cancer, multicentric disease, tumors fixed to the chest wall, or metastatic disease at baseline were ineligible.

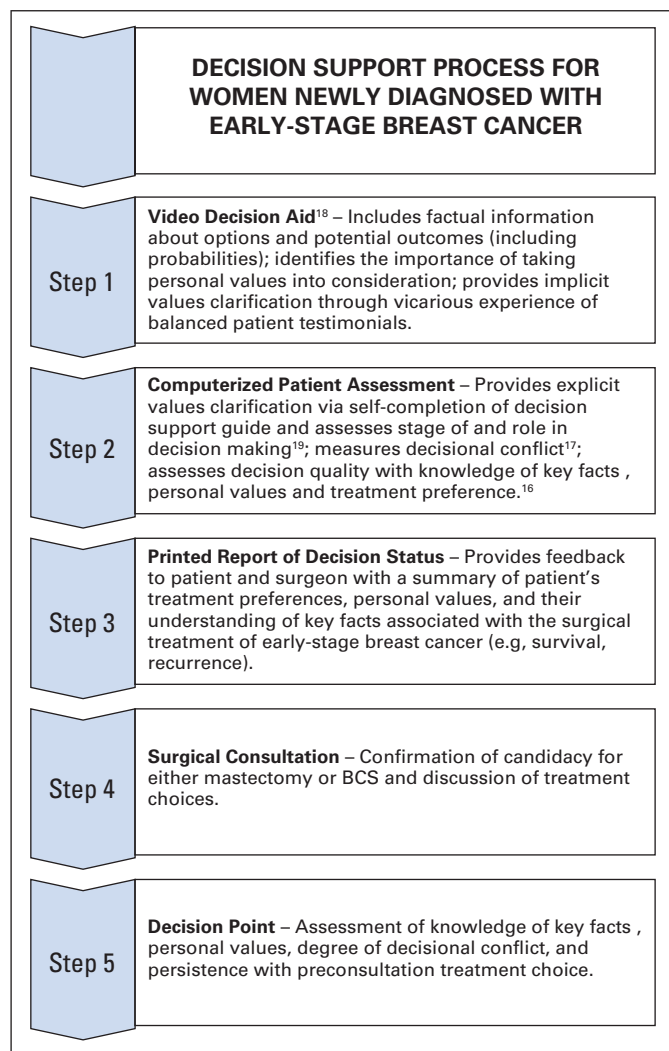


Fig 1. Our decision support process includes a number of steps, including a video decision aid with factual information, implicit and explicit values clarification and a feedback report. BCS, breast-conserving surgery.

It is standard practice at our center for women eligible for both options to view a 55-minute video decision aid (DA) before their surgical consultations. The DA provides information about surgical options, notes the importance of taking personal values into consideration, and provides balanced testimonials from women who chose either option. Patients also routinely complete a computerized intake questionnaire. The questions cover health history, preferred role in and stage of decision making, degree of decisional conflict, information comprehension, and treatment preference. A summary report of responses is supplied to providers before the consultation and is used to guide the conversation.

Study Design and Data Collection

This was a prospective observational cohort study approved by our Committee for Protection of Human Subjects. We did not randomly assign women to receive or not receive the DA because the purpose of this study was not to measure the effect of the intervention on patient knowledge, but to measure the degree to which informed women chose mastectomy, and to reveal their reasons for this choice.

For those consenting to the study, responses to our standard questionnaire became baseline data. Participants completed a second questionnaire after viewing the DA and before surgical consultation. This assessed the participant's knowledge, the personal values assigned to the attributes unique to each surgical option, level of decisional conflict, and preferred surgical option. Participants then proceeded to their consultation with a printed summary of their responses.

After surgery was scheduled, a follow-up questionnaire was administered by telephone to reassess decision quality (knowledge, values, and the chosen surgery) as well as decisional conflict and the actual role played in the decision. Participants were also asked whether the surgeon had discussed both options to reconfirm her eligibility for either choice. After surgery, participants' postoperative cancer stage was recorded using medical record review to take into account possible clinical contraindications to BCS.

Measures

Patient characteristics. Participants' sociodemographic characteristics, clinical history, and self-reported Charlson Comorbidity Index were collected in the baseline questionnaire.²⁰

Surgical treatment choice. Participants were asked which option they were leaning toward (mastectomy, BCS, or “unsure”) in the baseline questionnaire and post-DA questionnaire. In the follow-up questionnaire, they were asked to report their actual choice. For those whose surgical intent changed from post-DA to follow-up, an additional item assessed the reason for the switch.

Knowledge and values. Knowledge and values items were linked directly to the content of the video DA. The DA was developed by medical and decision experts and derived from literature review and national focus groups. Item and response formats were revised after cognitive testing with breast cancer survivors, pilot testing with patients at our center, and pilot testing with breast cancer survivors elsewhere.²¹

Knowledge. We included five multiple-choices items to assess participants' comprehension in the post-DA questionnaire. The key issues covered in the items were knowledge of survival, local recurrence, timing of surgery, and eligibility for the treatments. This was not meant as a comprehensive knowledge assessment, rather as a screen to highlight critical gaps in understanding.

Values. We included seven items that covered key attributes of the options and other issues identified by patients as important when making this decision. Participants used a discrete 10-point scale to assign an importance score [1 = “not at all important”; 10 = “very important”] to each item: “How important is it to you to: (1) keep your breast? (2) minimize chance of cancer coming back? (3) avoid radiation? (4) do everything possible? (5) minimize length of treatment? (6) do what doctor thinks is best? (7) remove breast for peace of mind?”].

Decisional conflict. Uncertainty about decision making was measured with the Decisional Conflict Scale (DCS). The DCS is a reliable scale that gauges uncertainty about the best course of action and factors contributing to that uncertainty (feeling uninformed, unclear about personal values, and

unsupported in decision making). The DCS can be scored from 0 (no decisional conflict) to 100 (high decisional conflict). Scores of 25 or less are associated with follow-through with decisions, whereas higher scores are associated with delays, decisional regret, and tendencies to blame the doctor for bad outcomes.^{22,23} The DCS can also discriminate between patients receiving different intensities of decision support.¹⁷

Decision-making role preference. At baseline and follow-up, one item was used to elicit desired participatory role; responses were obtained on a categorical scale.²⁴

Data Analysis

Descriptive statistics were computed for all variables. Demographic and clinical characteristics were summarized as the frequency of endorsed responses. The self-reported Charlson Comorbidity Index was summarized according to recommended algorithms.²⁰ *t* tests were used to assess group differences in continuous outcomes; reported *P* values are associated with two-tailed tests of significance. To examine the association between participants' values scores and the type of surgery they received, the authors used a logistic model with the value scores as predictors of receipt of mastectomy, controlling for clinical and predisposing factors (age, marital status, and stage of disease). SAS statistical software, version 9.2 (SAS Institute, Cary, NC), was used for all statistical analysis.

RESULTS

Response and Sample

Of 249 eligible women, 98 did not complete the post-DA questionnaire (44 declined, 21 ran out of time, and 33 had other reasons). Of the 151 women who enrolled and completed both baseline and

post-DA questionnaires, 26 did not complete the follow-up assessment (21 missed the time window, five withdrew), leaving 125 who completed questionnaires at all three time points. The enrollment rate of 50% (125 of 249 eligible) was low; however, there were no significant differences between responders and nonresponders.

The study sample (*n* = 125) was primarily white (98%) and well educated (74% at least some college). Forty-four (35%) chose mastectomy. Younger and married patients were positively associated with the choice for mastectomy (*P* ≤ .05). Patients with higher-stage breast cancers (II, III) were also more likely to choose mastectomy (*P* < .01). Education, comorbidities, and perceived role in decision making were not statistically different for participants choosing mastectomy (Table 1).

Treatment Preferences and Choices

The percentage of participants indicating a preference for mastectomy increased at each time point (22%, 31%, and 35%; Table 2). The number of women unsure about either choice was fairly high before (43%) and after the DA (38%). However, this uncertainty disappeared after the consultation with the surgeon (Table 2); of the 47 women who had been unsure after the DA, 33 chose BCS and 14 chose mastectomy.

Of the 78 women who had reported a definite preference for either mastectomy or BCS after the DA, 15 participants switched their choice after their consultation. Twelve switched from mastectomy to BCS; reported reasons were as follows: "After talking with the surgeon,

Table 1. Demographic and Clinical Characteristics (N = 125)

Characteristic	Total		Surgery				<i>P</i> *
	No.	%	Mastectomy (n = 44)		BCS (n = 81)		
	No.	%	No.	%	No.	%	
Age, years							.05
Mean	58		55		60		
SD	11.8		12.8		11.0		
Race/ethnicity							
White, non-Hispanic	123	98	43	98	80	99	.58
Other	2	2	1	2	1	1	
Education							
College graduate or more	51	41	19	43	32	40	.27
Some college	42	34	11	25	31	38	
High school or less	32	25	14	32	18	22	
Married or partnered	88	70	37	82	51	63	.01
Stage of disease†							
I	63	52	15	35	48	62	< .01
II	45	37	18	42	27	35	
III	13	11	10	23	3	4	
Medical comorbidities							
0	92	74	33	75	59	73	.90
1	22	18	8	18	14	17	
≥ 2	11	9	3	7	8	10	
Role in decision making							
Decided myself after listening to others	71	57	22	50	49	60	.36
Shared decision with others	49	39	19	43	30	37	
Someone else decided	5	4	3	7	2	2	

NOTE. Boldfacing indicates statistical significance.

**P* values by T-test for continuous and Fisher's Exact test for categorical characteristics.

†Stage of disease was finalized after definitive surgery.

Table 2. Preferred Treatment and Final Choice

Response	No. of Patients	Before Decision Aid		After Decision Aid*		After Consult†	
		No.	%	No.	%	No.	%
Mastectomy	28	28	22	39	31	44	35
BCS	43	43	34	39	31	81	65
Unsure	54	54	43	47	38	—	—

Abbreviation: BCS, breast-conserving surgery.

*Patient choice: before v after decision aid ($P = .05$).

†Patient choice: after decision aid v after consult ($P < .01$).

I found out it was a choice for me” ($n = 7$), “I have a better understanding of the options” ($n = 4$), and “The surgeon recommended another option” ($n = 1$). Three switched from BCS to mastectomy; their reported reasons were as follows: “The surgeon said I was not eligible for the other option” ($n = 2$) and “The surgeon recommended another option” ($n = 1$).

Knowledge Scores

After viewing the DA, participants’ knowledge scores were high (Table 3). No differences in knowledge scores were observed between participants choosing BCS (93%) and mastectomy (92%; t test $P = .68$).

Values

With each point increase in importance for the item “remove breast for peace of mind,” participants were more likely to have mastectomy (odds ratio [OR] = 2.2; 95% CI, 1.5 to 3.6). The item “avoid radiation” was also associated with the choice of mastectomy (OR = 1.5; 95% CI, 1.1 to 2.1). For the item “keep your breast,” participants were less likely to have mastectomy (OR = 0.7; 95% CI 0.5 to 0.9). When included in the multivariate model, other values items (“do what your doctor thinks is best,” “minimize length of treatment,” “minimize chance of cancer coming back,” and “do everything possible”) did not discriminate between participants choosing mastectomy and BCS (Fig 2). A sensitivity analysis excluding the seven patients who were not offered BCS as a surgical option, (leaving

118 patients) yielded similar ORs (2.2, 1.5, and 0.7) for the three values items that had a statistically significant association with surgery choice.

Decisional Conflict

Overall decisional conflict scores were high at baseline, and declined post-DA and again after the surgical consultation (Fig 3; paired t test $P < .01$). The reduction in overall decisional conflict scores was primarily driven by reductions on two subscales: feeling uninformed and unclear about personal values (paired t test $P < .01$). After the consultation, participants reported further declines in all subscales, particularly in the personal uncertainty subscale (paired t test $P < .01$). In general, participants choosing mastectomy had slightly lower decisional conflict scores, by 1 to 4 points, but these differences were not significant ($P > .05$).

Preference for Participation

The majority of participants (61%) reported participating in the surgical decision in a manner that matched their desired role measured at baseline. No significant differences in desired or actual roles were observed between participants choosing mastectomy and BCS.

After the surgical consultation, the majority of participants reported either (a) making the decision themselves after listening to the opinions of others (57%), or (b) sharing the decision (39%); only 4% reported that the decision was made by someone else. Of those who

Table 3. Patient Knowledge Scores After Decision Aid (N = 125)

Question	Correct Response	Patients Answering Correctly (%)
(1) On average, which patients with early-stage breast cancer live longer?	There is no difference between those who have mastectomy and those who have lumpectomy and radiation	98
(2) On average, how do the chances of having cancer come back in the breast or breast area compare between lumpectomy with radiation and mastectomy?	Slightly higher after lumpectomy with radiation	63
(3) If 100 women are treated with lumpectomy and radiation for early-stage breast cancer, about how many will have breast cancer come back in the treated breast in the 10 years after treatment?	5-15	91
(4) How many women with early-stage breast cancer are candidates to choose between lumpectomy and mastectomy?	Almost all (about 75%)	99
(5) For most women with early-stage breast cancer, how much would waiting 4 weeks to make a treatment decision affect their chances of survival?	A little or not at all	93

NOTE. Average score is 92%.

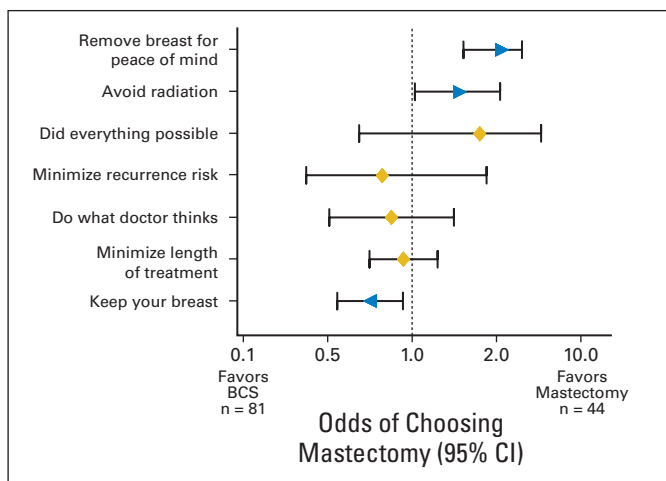


Fig 2. Logistic regression using patient value scores as predictors of surgical treatment choice. BCS, breast-conserving surgery.

reported sharing the decision, 93% said they shared the decision with their surgeon.

DISCUSSION

Women newly diagnosed with breast cancer were provided with current, comprehensive information about the risks and benefits of BCS and mastectomy, in a controlled, supportive setting. After viewing the DA, the women completed a self-directed exercise in explicit values clarification. Women were subsequently seen by surgeons who endorse a collaborative and informed decision-making process. This process resulted in high knowledge scores, significant associations between patient values and treatment choice, and low decisional conflict. Approximately one third of these informed women chose mastectomy, the more invasive and potentially disfiguring procedure.

The knowledge scores reported in this study were much higher than reported elsewhere. Fagerlin et al²⁵ conducted a large, population-based study of knowledge among women diagnosed with

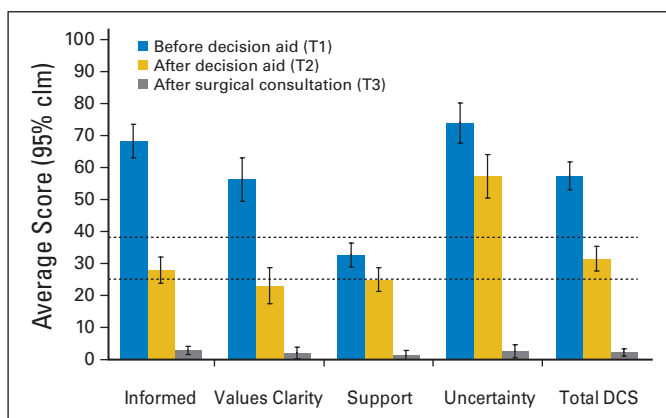


Fig 3. Changes in decisional conflict scores (n = 125). Time points: Before decision aid (T1), after decision aid (T2), and after surgical consultation (T3). Scores range from 0 (low decisional needs) to 100 (high decisional needs). Scores less than 25 are associated with implementing decisions; scores more than 38 are associated with decisional delay.

breast cancer, and found that respondents to a mailed survey demonstrated poor understanding of the key facts associated with their options. Only 21% responded correctly to a question about local recurrence; only 42% understood that survival rates were equivalent for the two surgical options. A small study by Sepucha et al²¹ of recent breast cancer survivors found that only 53% understood that survival was the same, and only 45% had an accurate sense for the magnitude of the local recurrence risk.

Even in this homogeneous patient population, women felt differently about the importance of the attributes and outcomes associated with the surgical options. Thirty-two percent of the women who received BCS and 89% of the women who received mastectomy did not feel strongly about keeping their breast (eg, scored < 5). Gaining peace of mind by removing their breasts and avoiding radiation were rated significantly higher by participants choosing mastectomy. Other attributes and outcomes, such as avoiding local recurrence, did not discriminate between those choosing mastectomy over BCS.

An innovative component of this study is that clinicians were provided with a summary report including information about their patient's knowledge, values, and overall treatment preferences for use during the consultation. Having the report in advance allowed clinicians to address knowledge gaps, discuss values, and reduce uncertainty about which surgery to choose. The notable reduction in overall decisional conflict scores at each time point supports the assertion that DAs are helpful in preparing women for the appointment, but do not replace professional consultation.

Several studies have documented an association between women's treatment choices and their views about cosmesis and body image.^{9,21,26,27} It is important to note that this study took place at an institution that offers immediate breast reconstruction, and women are routinely informed of this option along with the options of mastectomy alone, mastectomy with delayed reconstruction, or BCS. Women considering mastectomy with immediate reconstruction were offered additional decision support to inform them of reconstruction options, before their consultation with a plastic surgeon. Both the availability and the local level of expertise in immediate breast reconstruction are not available at many sites in the United States and may influence the number of women who choose mastectomy. Of the 44 participants who chose mastectomy, 27 (61%) had mastectomy alone, and 17 (39%) had mastectomy with immediate reconstruction. Further exploration is needed into the possible association between the availability of immediate reconstruction and the choice of mastectomy.

The importance of avoiding a local recurrence has also been associated with the choice of mastectomy in several studies.^{15,26,28} It is likely that the lack of the influence of local recurrence rates on surgery choice in this sample is a result of the fact that surgeons present the chance as low for both options.

Katz¹⁵ found that increased patient participation in decision making was associated with choosing mastectomy over BCS. In the study reported here, the vast majority (96%) reported that they either made the decision on their own after listening to the opinions of others, or they shared the decision with their surgeon. Patient engagement in the decision-making process was built into the care pathway, which may account for the lack of difference between BCS and mastectomy patients in terms of their reported role in decision making. The high rates of reported involvement in the decision lend support to

the use of DAs as an effective means of providing patient-centered care to women with early-stage breast cancer.

Studies that have used epidemiologic data sources such as the Surveillance, Epidemiology, and End Results (SEER) database have offered insight into possible correlates with treatment choice, including race, socioeconomic status, education level, and living in a state where informing breast cancer patients of alternatives is mandated.²⁹ However, such studies demonstrate trends rather than revealing actual influences on patients, such as personal values for the options' attributes/outcomes as was shown here.

This study was conducted at a single academic medical center where decision support is systematically incorporated into the clinical care process. Women were therefore not randomly assigned to receive or not receive the DA, as testing the efficacy of the DA was not a goal of the researchers. Compelling data already exist to support the use of DAs among women facing values-sensitive decisions such as breast cancer surgery.^{17,30} Although the response rate was low, this is a vulnerable population to engage in survey research.

External validity may be limited by the homogeneity of the sample. Prior studies have suggested that race is an important factor in decision role, treatment choice, and survival.²⁹ Further studies are needed in a more diverse cohort to see whether these results are similar for women in different parts of the country.

Both researchers and clinicians often view higher rates of breast-conserving treatment as indicative of better care.¹⁰ Lanz et al¹⁰ caution researchers to "move away from a primary focus on rates of mastectomy versus BCS, widening the research lens to view the degree to which women are being fully informed." This study goes even further

to highlight the importance not only of informing patients, but also of eliciting and tailoring care to individual patients' values and treatment preferences. When women fully comprehend the key facts, many will find that mastectomy, the more invasive procedure, is their preferred choice.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: E. Dale Collins, Caroline P. Moore, Kate F. Clay, Stephen A. Kearing, Annette M. O'Connor, Hilary A. Llewellyn-Thomas, Karen R. Sepucha

Administrative support: Caroline P. Moore, Kate F. Clay, Stephen A. Kearing

Provision of study materials or patients: Kate F. Clay, Richard J. Barth Jr

Collection and assembly of data: Kate F. Clay, Stephen A. Kearing

Data analysis and interpretation: E. Dale Collins, Caroline P. Moore, Stephen A. Kearing, Annette M. O'Connor, Hilary A. Llewellyn-Thomas, Richard J. Barth Jr, Karen R. Sepucha

Manuscript writing: E. Dale Collins, Caroline P. Moore, Stephen A. Kearing, Annette M. O'Connor, Hilary A. Llewellyn-Thomas, Karen R. Sepucha

Final approval of manuscript: E. Dale Collins, Caroline P. Moore, Kate F. Clay, Stephen A. Kearing, Annette M. O'Connor, Hilary A. Llewellyn-Thomas, Richard J. Barth Jr, Karen R. Sepucha

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