Published in final edited form as:
J Am Coll Surg. 2012 January ; 214(1): 1–10. doi:10.1016/j.jamcollsurg.2011.09.017.

Decision Making about Surgery for Early Stage Breast Cancer

Clara N Lee, MD, MPP[1], **Yuchiao Chang, PhD**[4], **Nesochi Adimorah**[2], **Jeff Belkora, PhD**[3], **Beverly Moy, MD, MPH**[5], **Ann Partridge, MD, MPH**[6], **David W. Ollila, MD**[2], and **Karen Sepucha, PhD**[7]

[1]Division of Plastic and Reconstructive Surgery, Lineberger Comprehensive Cancer Center, Sheps Center for Health Services Research, Chapel Hill, NC

[2]Department of Surgery, University of North Carolina, Chapel Hill, NC

[3]Institute for Health Policy Studies, University of California, San Francisco, CA

[4]Department of General Medicine, Massachusetts General Hospital (MGH), Harvard Medical School (HMS), Boston, MA

[5]MGH Cancer Center, HMS, Boston, MA

[6]Dana-Farber Cancer Institute, Brigham and Women's Hospital, HMS, Boston, MA

[7]Health Decision Sciences Center, MGH, HMS, Boston, MA

Abstract

Background—Practice variation in breast cancer surgery has raised concerns about the quality of treatment decisions. We sought to evaluate the quality of decisions about surgery for early stage breast cancer by measuring patient knowledge, concordance between goals and treatments, and involvement in decisions.

Study Design—A mailed survey of Stage I/II breast cancer survivors was conducted at four sites. The Decision Quality Instrument measured knowledge, goals, and involvement in decisions. A multivariable logistic regression model of treatment was developed. The model-predicted probability of mastectomy was compared to treatment received for each patient. Concordance was defined as having mastectomy and predicted probability >=0.5 or partial mastectomy and predicted probability <0.5. Frequency of discussion about partial mastectomy was compared to discussion about mastectomy using chi-squared tests.

Results—440 patients participated (59% response rate). Mean overall knowledge was 52.7%. 45.9% knew that local recurrence risk is higher after breast conservation. 55.7% knew that survival is equivalent for the two options. Most participants (89.0%) had treatment concordant with their goals. Participants preferring mastectomy had lower concordance (80.5%) than those preferring partial mastectomy (92.6%, p=0.001). Participants reported more frequent discussion of partial mastectomy and its advantages than of mastectomy. 48.6% reported being asked their preference.

Correspondence address: Clara N. Lee, Assistant Professor of Surgery, University of North Carolina CB 7195, Chapel Hill, NC 27599-7195, Phone: 919-966-7729 fax: 919-966-3814, cnlee@med.unc.edu.

Disclosure Information: Nothing to disclose.

Abstract presented at the Annual Meeting of the Society for Medical Decision Making, LOCATION, MONTH 2009.

Conclusions—Breast cancer survivors had major knowledge deficits, and those preferring mastectomy were less likely to have treatment concordant with goals. Patients perceived that discussions focused on partial mastectomy, and many were not asked their preference. Improvements in the quality of decisions about breast cancer surgery are needed.

Introduction

Geographic variation in rates of mastectomy and breast conserving surgery[1,2] has led to concerns about the quality of decisions about surgical treatment for early stage breast cancer.[3] Even since the dissemination of recommendations in favor of breast conservation therapy in the early 1990s, rates of mastectomy and partial mastectomy have varied by region, age, and race.[4-6] The decision about type of surgery for early stage breast cancer is considered a “preference-sensitive decision” for patients who are clinically eligible for either option, because the best choice depends primarily on the patient's preferences.[7] For preference-sensitive decisions, an international consensus process has defined decision quality as the degree to which a decision is *informed* and *concordant* with patient preferences.[8, 9]

The quality of decisions about surgical treatment for early stage breast cancer in the United States is unclear. Breast cancer patients have reported unfulfilled information needs[10] and shown significant deficits in knowledge about treatments.[11-13] Studies of patient knowledge have been limited by a lack of validated knowledge measures specific to the breast cancer surgery decision[12, 14] and a failure to consider specific treatment attributes besides recurrence and survival.[11, 15-18] Validated and specific measures of preference concordance are also lacking.[19, 20] Although several studies have reported on which patient concerns affect decisions about surgery for breast cancer, [21-23] few have attempted to quantify the degree to which treatments reflect patient preferences.[24]

The purpose of this study was to evaluate the quality of decisions about surgery for early stage breast cancer. We specifically sought to measure patient knowledge about surgical options and to evaluate the degree to which treatments were concordant with patient preferences and goals. Secondary objectives were to identify factors associated with knowledge and to describe patient involvement in the decision making process.

Methods

Study design

We conducted a cross-sectional mailed survey of recent breast cancer survivors at four academic medical centers from October 2008 to February 2011. The institutional review board at each institution approved the study.

Patient Population

Subjects included a sample of adult women with a history of early-stage invasive breast cancer (Stages I, II) diagnosed one to three years prior to contact (2005 to 2010) and treated at one of four institutions (Dana-Farber Cancer Institute, Massachusetts General Hospital, University of California San Francisco, and University of North Carolina at Chapel Hill).

We excluded patients who had Stage III or IV disease, DCIS only, bilateral breast cancer, or neoadjuvant chemotherapy, and those who could not speak and read English.

Study Design and Procedures

Eligible patients were identified through each site's cancer registry. Permission to contact and confirmation of eligibility to participate were requested from each patient's provider. A modified Dillman survey method was followed.[25] Patients were mailed an introductory letter, survey instrument, consent forms, opt-out card, and packet of breast cancer awareness postage stamps (worth approximately $5). After two weeks, study staff members called patients who had not opted out, to discuss the study, answer questions, and encourage survey completion. After another two weeks, a reminder packet was mailed to non-responders. Participants received a thank you note with another packet of postage stamps. Each participant provided written informed consent.

Measures

The survey contained questions about demographics, clinical history, preferred treatment, perception of being informed, and the Decision Quality Instrument. Demographic, medical, and treatment data were obtained from the cancer registry. When a patient's report conflicted with the registry on a clinical issue (e.g. stage), the medical record was examined.

Breast Cancer Surgery Decision Quality Instrument (BCS-DQI)—The BCS-DQI contains items that cover three domains – knowledge, goals and concerns, and involvement in decisions. (See appendix 1). The domains were based on a consensus of clinicians, consumers, and medical decision making experts, which defined decision quality as the degree to which the patient is informed, meaningfully involved in decision making, and receiving care that matches her goals.[8] The instrument has demonstrated feasibility of administration, acceptability to patients, discriminant validity, content validity (based on provider and patient reports), and strong retest reliability (intraclass correlation coefficient of 0.81) in this sample.[26] The instrument refers to partial mastectomy as “lumpectomy” to be more comprehensible to patients.

1. Knowledge. 12 multiple choice or fill-in-the-blank items about breast cancer and the local treatment options including local recurrence, survival, and side effects.
2. Goals and concerns. 6 items rated on a scale from 0 (not at all important) to 10 (extremely important).
3. Involvement. 7 multiple choice items about the content of discussions with providers and how involved the patient was in decision making.

Preferred treatment—Single item: “Which option was your personal preference?” with responses “Lumpectomy only”, “Lumpectomy with radiation”, “Mastectomy”, or “I am not sure”.

Treatment received—This was defined as the final treatment received, according to the cancer registry (and the chart, if the patient's report conflicted with the registry). In patients who had partial mastectomy followed by mastectomy, treatment received was defined as mastectomy.

Perception of being informed—Single item: “On a scale from 0 to 10, where 10 means extremely well informed and 0 means not informed at all, how informed did you feel about surgical options for breast cancer?”

Statistical Analysis

Knowledge—The number of correct knowledge items was divided by the total number of knowledge items and multiplied by 100, resulting in a knowledge score from 0% to 100%

for each patient. Quantitative, fill-in-the-blank items were considered correct if they fell within a range determined *a priori* by medical experts based on clinical evidence. An "I am not sure" response was considered incorrect, and missing responses were imputed with 1/k, where k was the number of possible responses. Knowledge scores were calculated for every respondent who completed at least 6 of 12 items.

Chi-square tests were used to compare the percentage of partial mastectomy patients with correct answers to the percentage of mastectomy patients with correct answers, for each question. A two-sample t-test was used to compare the mean knowledge scores between groups.

To identify characteristics associated with higher knowledge, univariate analysis with a two-sample t-test or analysis of variance was performed. A multivariable linear regression model was created, including variables significant at the 0.05 level from univariate analysis. Association between perception of being informed and actual overall knowledge was summarized using Pearson's correlation coefficient.

Concordance score—To estimate the extent to which treatment received was associated with a patient's goals, we used the following approach, which has been described previously. [27] A multivariable logistic regression model of treatment (partial mastectomy versus mastectomy) was developed, including stage and the six goals and concerns as candidate predictors. Goals and concerns were included based on the premise that preference sensitive decisions should incorporate the personal goals and concerns of the patient. Stage was included in the model to account for clinical appropriateness. Missing responses about goals were imputed from other available goal items.[28] The final concordance model included stage and those goals and concerns that were significant at the 0.05 level on multivariate analysis. The model-predicted probability of mastectomy was then calculated for each patient based on the logistic regression model estimates. Patients with a predicted probability >=0.5 who had mastectomy and those with a predicted probability <0.5 who had partial mastectomy were classified as having concordant care. The proportion of patients with concordant care was calculated for the sample. For these analyses, we excluded patients who had partial mastectomy followed by mastectomy.

Involvement—The frequency of discussion about partial mastectomy and its pros and cons was compared to the frequency of discussion about mastectomy and its pros and cons using chi-squared tests.

Results

Patient characteristics

We identified 769 potential participants, of whom providers excluded 23 (3.0%) as ineligible or unable to fully participate. Of the remaining 746 patients, 440 (59%) responded (Table 1). Respondents were more likely to be white than non-responders (85.2% vs. 71.4%, p<0.0001). Most respondents (N=272, 61.8%) had undergone partial mastectomy; 111 respondents (25.2%) had undergone initial mastectomy, and 57 respondents (13.0%) had undergone partial mastectomy followed by mastectomy (primarily to obtain negative margins). The 57 patients who had undergone partial mastectomy followed by mastectomy were classified as having undergone mastectomy.

Knowledge

Overall, participants' mean knowledge score was 52.7% (SD 21.8%) (Table 2). Fifty-eight percent of participants scored 50% or higher.

Local recurrence—About half of participants (45.9%) knew that the risk of local recurrence is higher after partial mastectomy with radiation than after mastectomy. The remaining participants answered “there is no difference” (28.2%) or “I am not sure” (24.5%). Participants who had partial mastectomy were less likely to answer this question correctly (p<0.0001).

A minority of participants could accurately estimate the 10 year risk of local recurrence after either surgical option. For the risk of local recurrence after partial mastectomy and radiation, 36.8% responded correctly (5 to 15% was considered correct). Incorrect responses were mostly overestimations (18.6%), and women who had partial mastectomy were more likely to answer correctly (p=0.016). For the risk of local recurrence after mastectomy, 37.5% responded correctly (2 to 10% was considered correct). Incorrect responses were split between under (14.8%) and over (14.6%) estimations. Frequency of correct responses did not vary by treatment. For both questions, approximately one-third responded “I am not sure”.

Survival—About half of participants (55.7%) knew that partial mastectomy with radiation and mastectomy resulted in equivalent survival, and 29.3% responded “I am not sure”. Participants who had undergone partial mastectomy were more likely to answer this question correctly (p<0.0001).

Specifics of breast conservation therapy—Most (69.1%) knew that partial mastectomy was more likely to require reoperation for margins. A minority knew how many women who have partial mastectomy and radiation are very satisfied with appearance of the breast, with 28.4% correctly responding “most”, 32.5% responding “some” or “a few”, 5.0% responding “none”, and 32.1% responding “I am not sure”. Participants who had partial mastectomy were more likely to answer this question correctly. A minority knew the approximate prevalence of serious radiation side effects, with 26.8% correctly responding “fewer than 5%”, 8.4% responding “5-10%”, 4.3% responding “10% or higher”, and 58.4% responding “I am not sure”. Women who had partial mastectomy were more likely to answer this question correctly.

On multivariable analysis, younger age, white race, higher education, higher income, lower stage of disease, treatment with partial mastectomy, and more recent diagnosis were associated with higher knowledge (Table 3). Overall, participants felt they were well-informed (mean 8.7 out of 10, SD 1.7), but the perception of being informed did not correlate with their overall knowledge score (Pearson's coefficient 0.08, p=0.10). Knowledge scores did not vary significantly by site (Table 3).

Concordance between goals and treatment

Receipt of mastectomy was associated with three of the goals/concerns on multivariable analysis (Table 4). The goals “remove your breast for peace of mind” and “avoid radiation” were positively associated with mastectomy, while the goal “keep your breast” was negatively associated with mastectomy. The overall concordance score, or percentage of patients who got the treatment predicted by the model, was 89.0%. Concordance was lower for mastectomy than for partial mastectomy. Specifically, women for whom the model predicted mastectomy received mastectomy 80.5% of the time, whereas women for whom the model predicted partial mastectomy received partial mastectomy 92.6% of the time (p=0.001). Treatment choice did not vary significantly by site (Table 3).

Involvement in decision making

Most participants (90.0%) reported that their providers discussed partial mastectomy as an option (Table 5). Fewer (68.0%) reported a discussion of mastectomy as an option ($p<0.0001$), and 58.6% reported a discussion of both options. More participants reported discussion about the reasons *for partial mastectomy* (75.5%) than discussion of the reasons *for mastectomy* (53.9%, $p<0.0001$). Conversely, fewer participants reported discussion of the reasons *against partial mastectomy* (36.1%) than discussion of reasons *against mastectomy* (49.3%, $p=0.0002$). Most participants reported that the provider made a treatment recommendation (83.2%). Less than half (48.6%) reported that their provider asked their treatment preference.

Discussion

For breast surgery, the quality of decisions can be judged by the extent to which patients are informed, involved in decision making, and undergoing treatments that reflect their goals. This study is the first to fully describe the quality of breast cancer surgery decisions along these three dimensions. In general, participants had significant deficits in knowledge one to three years after diagnosis, including knowledge about local recurrence and survival. Their reports of discussions with providers suggested that patients were not always meaningfully involved in selecting treatments. Most participants had treatment that was concordant with their goals, but women who preferred mastectomy were less likely to have concordance than women who preferred partial mastectomy.

Patients in this sample lacked knowledge regarding approximately half of the information that providers had identified as critical. Although we would expect patients to have forgotten some information since surgery (particularly the specific risk estimates), even the gist or summary information questions showed large knowledge gaps. For example, only half of the sampled patients knew that survival was the same for breast conservation therapy and mastectomy. Women who had partial mastectomy were less knowledgeable about local recurrence than women who had mastectomy, despite being equally concerned about it. We found this somewhat concerning, since patients who opt for partial mastectomy need to be aware of their slightly higher risk of local recurrence.

Our findings regarding knowledge about recurrence and survival are similar to other reports. In one population-based study (limited to Detroit and LA), 26% of breast cancer survivors knew that local recurrence was higher after breast conservation therapy, and 48% knew that survival was equivalent for breast conservation therapy and mastectomy.[11] At one academic center, 45% of survivors knew that local recurrence was higher after breast conservation therapy, and 53% knew about the survival equivalence.[29] Our study confirms these findings, using a tested and validated knowledge measure.

Concordance between treatments and goals was relatively high, but a substantial minority of participants (18%) received treatment they did not prefer, and women who preferred mastectomy were more likely to receive discordant care. Some of this discordance may be related to providers' beliefs in the advantages of breast conservation therapy. Patient reports on the interaction revealed that one-third of participants could not recall ever being presented with the option of mastectomy. About half of respondents reported that they were not asked for their treatment preference. In fact, they recalled providers making a recommendation twice as often as asking for patients' preferences. Some of the patients who had mastectomy may have had contraindications to breast conservation (e.g., tumor size relative to breast size, prior chest radiation). We attempted to minimize this possibility by having providers confirm eligibility, including stage in the treatment model, and excluding patients who had partial mastectomy followed by mastectomy from the concordance analysis.

Women who prefer mastectomy may be lacking support from some providers and requiring greater effort to obtain the treatments they prefer. Breast surgeons tend to prefer breast conservation therapy to mastectomy,[30] and they report frequent conflicts with patients who are eligible for breast conservation but want mastectomy.[31] A growing body of research is finding that some women who are highly informed and have no clinical contraindication to breast conservation still prefer mastectomy.[24,32] In addition, greater involvement in the decision making process has been associated with choice of mastectomy.[32, 33]

The retrospective design of this study has important limitations. Participants may have forgotten information, so knowledge at the time of decisions may have been higher than what we measured. In addition, participants' reports of their goals and concerns may have been affected by recall bias, in which a person's experiences after an event influence her memories and perceptions of that event. For example, a patient who chose breast conservation therapy and then experienced substantial anxiety with each surveillance mammogram may have been more likely to report a high level of concern about recurrence than she actually had at the time of decision making. A prospective study measuring decision quality closer to the time of decisions would shed light on the direction and magnitude of these potential biases.

Recall bias could also affect participants' report of their interaction with providers, with patients tending to have more memory of discussions about the treatments they received. Evaluating this would be possible through comparison of patient report to documentation in the medical record or to audio-recordings of the clinical encounter. Such approaches could provide insight into these processes in the future.

The study population had relatively high proportions of white, younger, educated, and higher-income patients. The sample came exclusively from academic medical centers and included English-speaking women only. We are uncertain how other populations would differ, in terms of patient goals and treatments received. Since our population had relatively good access to health care, we hypothesize that other more vulnerable populations may have larger knowledge deficits and lower concordance. Some variation in patient knowledge and preferences by site may have existed, despite our attempts to achieve uniformity by using the same eligibility criteria, enrollment approaches, and data collection methods across sites. We did not find differences in knowledge or treatment by site, but the sample size was not large enough to detect small differences. Future studies should seek to replicate or disconfirm our findings in more diverse settings and with more diverse populations.

Making improvements in the quality of breast cancer surgical decisions will require interventions to enhance patient knowledge and promote incorporation of preferences into treatment decisions. Decision aids are tools designed to inform patients about key facts, help them clarify preferences, and prepare them for interaction with providers. They have proven effective at improving knowledge, reducing decisional conflict, and increasing participation in decisions.[34] Specific decision aids for breast cancer surgery have demonstrated improvements in knowledge about recurrence and survival.[12, 14] Communication aids, such as question lists and consultation audio-recordings, increase question-asking and information recall, respectively.[35, 36] Integration of decision and communication aids into the routine delivery of breast cancer care has been successful at some centers.[24, 37, 38]

In conclusion, our study demonstrated that early stage breast cancer survivors had deficits in breast cancer knowledge, and those who preferred mastectomy were less likely to receive treatment that was concordant with their preferences. Patients recalled the discussion of surgical options as tending to focus on breast conservation therapy and its advantages, and many patients reported they were not asked for their treatment preference. Overall, improvements in the quality of decisions about surgery for early stage breast cancer are needed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Research support: Drs. Belkora, Lee, and Sepucha were supported by a grant from the not-for-profit Foundation for Informed Medical Decision Making. Dr. Lee was supported by NIH/NCRR 1KL2RR025746.

References

1. The Dartmouth Atlas of Health Care: Inpatient mastectomy rates for cancer per 1,000 female Medicare enrollees: The Dartmouth Institute for Health Policy and Clinical Practice. May. 2011 http://www.dartmouthatlas.org/data/table.aspx?ind=95
2. Nattinger AB, Gottlieb MS, Veum J, et al. Geographic variation in the use of breast-conserving treatment for breast cancer. N Engl J Med. 1992; 326:1102–1107. [PubMed: 1552911]
3. Wennberg JE, O'Connor AM, Collins ED, et al. Extending the P4P agenda, part 1: how Medicare can improve patient decision making and reduce unnecessary care. Health Aff (Millwood). 2007; 26:1564–1574. [PubMed: 17978377]
4. Consensus statement: treatment of early-stage breast cancer. National Institutes of Health Consensus Development Panel. J Natl Cancer Inst Monogr. 1992:1–5.
5. Hiotis K, Ye W, Sposto R, et al. The importance of location in determining breast conservation rates. Am J Surg. 2005; 190:18–22. [PubMed: 15972165]
6. Albain KS, Green SR, Lichter AS, et al. Influence of patient characteristics, socioeconomic factors, geography, and systemic risk on the use of breast-sparing treatment in women enrolled in adjuvant breast cancer studies: an analysis of two intergroup trials. J Clin Oncol. 1996; 14:3009–3017. [PubMed: 8918499]
7. Wennberg J, Fisher E, Skinner J. Geography and the debate over Medicare reform. Health Aff. 2002; (Supp Web Exclusives):W94–114.
8. Sepucha KR, Fowler FJ Jr, Mulley AG Jr. Policy support for patient-centered care: the need for measurable improvements in decision quality. Health Aff (Project Hope). 2004; (Suppl Web Exclusive):VAR54–62.
9. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ. 2006; 333:417. [PubMed: 16908462]
10. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. JAMA. 1997; 277:1485–1492. [PubMed: 9145723]
11. Fagerlin A, Lakhani I, Lantz PM, et al. An informed decision? Breast cancer patients and their knowledge about treatment. Patient Educ Couns. 2006; 64:303–312. [PubMed: 16860523]
12. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. JAMA. 2004; 292:435–441. [PubMed: 15280341]
13. Street RJ, Voigt B, Geyer CJ, et al. Increasing patient involvement in choosing treatment for early breast cancer. Cancer. 1995; 76:2275–2285. [PubMed: 8635032]
14. Goel V, Sawka C, Thiel E, et al. Randomized trial of a patient decision aid for choice of surgical treatment for breast cancer. Med Decis Making. 2001; 21:1–6. [PubMed: 11206942]
15. Street RJ, Voigt B. Patient participation in deciding breast cancer treatment and subsequent quality of life. Med Decis Making. 1997; 17:298–306. [PubMed: 9219190]

16. Hawley ST, Fagerlin A, Janz NK, et al. Racial/ethnic disparities in knowledge about risks and benefits of breast cancer treatment: does it matter where you go? Health Serv Res. 2008; 43:1366–1387. [PubMed: 18384361]
17. Siminoff LA, Fetting JH, Abeloff MD. Doctor-Patient communication about breast cancer adjuvant therapy. J Clin Oncol. 1989; 7:1192–1200. [PubMed: 2671280]
18. Bluman LG, Borstelmann NA, Rimer BK, et al. Knowledge, satisfaction, and perceived cancer risk among women diagnosed with ductal carcinoma in situ. J Womens Health Gend Based Med. 2001; 10:589–598. [PubMed: 11559456]
19. Sepucha K, Ozanne EM. How to define and measure concordance between patients' preferences and medical treatments: A systematic review of approaches and recommendations for standardization. Patient Educ Couns. 78:12–23. [PubMed: 19570647]
20. Lee CN, Dominick R, Levin CA, et al. Development of instruments to measure the quality of breast cancer treatment decisions. Health Expect. 13:258–272. [PubMed: 20550591]
21. Molenaar S, Oort F, Sprangers M, et al. Predictors of patients' choices for breast-conserving therapy or mastectomy: a prospective study. Br J Cancer. 2004; 90:2123–2130. [PubMed: 15150557]
22. Katz SJ, Lantz PM, Zemencuk JK. Correlates of surgical treatment type for women with noninvasive and invasive breast cancer. J Womens Health Gend Based Med. 2001; 10:659–670. [PubMed: 11571095]
23. Figueiredo MI, Cullen J, Hwang YT, et al. Breast cancer treatment in older women: does getting what you want improve your long-term body image and mental health? J Clin Oncol. 2004; 22:4002–4009. [PubMed: 15459224]
24. Collins ED, Moore CP, Clay KF, et al. Can women with early-stage breast cancer make an informed decision for mastectomy? J Clin Oncol. 2009; 27:519–525. [PubMed: 19114703]
25. Dillman, D. Mail and Telephone Surveys: The Tailored Design Method. Vol. Vol 2nd edition. John Wiley & Sons; 1999.
26. Sepucha, K.; Chang, Y.; Cosenza, C., et al. Validation of knowledge measures for breast cancer treatment decisions. Presented at 31st Annual Meeting of the Society for Medical Decision Making; Los Angeles, CA. October 20, 2009; (abstract); Manuscript entitled “Measuring decision quality: psychometric evaluation of a new instrument for breast cancer surgery” to BMJ Quality and Safety on July 19, 2011
27. Barry M, Fowler FJ, Mulley AJ, et al. Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. Med Care. 1995; 33:771–782. [PubMed: 7543639]
28. Dempster AP, L N, Rubin DB. Maximum likelihood from incomplete data via the EM algorithm. J R Stat Soc. 1977; 39:1–38.
29. Sepucha K, Ozanne E, Silvia K, et al. An approach to measuring the quality of breast cancer decisions. Patient Educ Couns. 2007; 65:261–269. [PubMed: 17023138]
30. Katz SJ, Lantz PM, Janz NK, et al. Surgeon perspectives about local therapy for breast carcinoma. Cancer. 2005; 104:1854–1861. [PubMed: 16161056]
31. Opatt D, Morrow M, Hawley S, et al. Conflicts in decision-making for breast cancer surgery. Ann Surg Oncol. 2007; 14:2463–2469. [PubMed: 17510771]
32. Katz SJ, Lantz PM, Janz NK, et al. Patterns and correlates of local therapy for women with ductal carcinoma-in-situ. J Clin Oncol. 2005; 23:3001–3007. [PubMed: 15860856]
33. Hawley ST, Griggs JJ, Hamilton AS, et al. Decision involvement and receipt of mastectomy among racially and ethnically diverse breast cancer patients. J Natl Cancer Inst. 2009; 101:1337–1347. [PubMed: 19720966]
34. O'Connor A, Stacey D, Rovner D, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2001; (3) CD001431.
35. Kinnersley P, Edwards A, Hood K, et al. Interventions before consultations for helping patients address their information needs. Cochrane Database Syst Rev. 2007; (3) CD004565.
36. Pitkethly M, Macgillivray S, Ryan R. Recordings or summaries of consultations for people with cancer. Cochrane Database Syst Rev. 2008; (3) CD001539.

37. Belkora JK, Loth MK, Volz S, et al. Implementing decision and communication aids to facilitate patient-centered care in breast cancer: a case study. Patient Educ Couns. 2009; 77:360–368. [PubMed: 19850438]

38. Belkora JK, Teng A, Volz S, et al. Expanding the reach of decision and communication aids in a breast care center: A quality improvement study. Patient Educ Couns. 2011; 83:234–239. [PubMed: 20696543]

Table 1

Demographic and Treatment Characteristics of Study Sample

	All		Partial mastectomy		Mastectomy	
	n=440		n=272		n=168	
Characteristic	**n**	**%**	**n**	**%**	**n**	**%**
Age, y, mean (SD)	54.9 (11.3)		56.3 (11.9)		52.8(10.0)	
Months since diagnosis (SD)	30.8 (9.8)		31.0 (10.)		30.6 (9.5)	
Race						
White	365	83.0	232	85.3	133	79.2
Black	35	8.0	17	6.3	18	10.7
Other	40	9.1	23	8.5	17	10.1
Education						
High school or less	55	12.5	33	12.1	22	13.1
Some college	106	24.1	63	23.2	43	25.6
College graduate	279	63.4	176	64.7	103	61.3
Annual income						
<30,000	59	13.4	40	14.7	19	11.3
30,000-59,999	87	19.8	50	18.4	37	22.0
60,000-100,000	107	24.3	65	23.9	42	25.0
>100,000	160	36.4	97	35.7	63	37.5
Not available	27	6.1	20	7.4	7	4.2
Marital status						
Partnered	297	67.5	176	64.7	121	72.0
Other	141	32.0	95	34.9	46	27.4
not available	2	0.5	1	0.4	1	0.6
Stage						
I	265	60.2	183	67.3	82	48.8
II	175	39.8	89	32.7	86	51.2
Adjuvant treatment						
Chemotherapy	192	43.6	100	36.8	92	54.8

	All		**Partial mastectomy**		**Mastectomy**	
	n=440		**n=272**		**n=168**	
Characteristic	**n**	**%**	**n**	**%**	**n**	**%**
Hormone therapy	257	58.4	159	58.5	98	58.3
Radiation	243	55.2	256	94.1	37	22.0
Receptor Status						
Positive	370	84.1	231	84.9	139	82.7
Negative	70	15.9	41	15.1	29	17.3

Table 2
Knowledge of Specific Topics about Surgery for Early Stage Breast Cancer, by Treatment

		Patients answering correctly, %		
	All	Partial mastectomy	Mastectomy	
Question (correct answer)[*]	**n=440**[*]	**n=272**	**n=168**	**p Value**
For most women with early breast cancer, how much would waiting 4 weeks to make a treatment decision affect survival? (A little or not at all.)	59.8	59.6	60.1	0.91
With treatment, about how many women diagnosed with early breast cancer will die of breast cancer ? (Most will die of something else.)	70.9	73.9	66.1	0.08
After which treatment is a woman more likely to need another operation to remove the tumor? (Lumpectomy)	69.1	60.7	82.7	<0.0001
How many women are very satisfied with the way their breast looks after lumpectomy and radiation? (Most)	28.4	38.6	11.9	<0.0001
On average, which women with early breast cancer live longer? (There is no difference.)	55.7	60.7	47.6	0.007
Which women have a higher chance of having cancer come back in the breast that has been treated? (Women who had lumpectomy and radiation.)	45.9	37.9	58.9	<0.0001
After a lumpectomy, what is the usual schedule for traditional radiation? (5 days a week for 5 to 6 weeks.)	62.5	76.8	39.3	<0.0001
Out of 100 women who have radiation after lumpectomy, how many will have a serious side effect, such as another cancer, heart or lung problem? (Fewer than 5)	26.8	33.8	15.5	<0.0001
For each of the following, mark whether or not some women have this side effect from radiation after lumpectomy.				
Fatigue (Yes)	87.7	92.3	80.4	0.0002
Darker skin (Yes)	78.0	83.5	69.0	0.0004
Breast feels harder and thicker. (Yes)	67.7	75.7	54.8	<0.0001
Migraines (No)	41.6	48.2	31.0	0.0004
If cancer comes back in the treated breast after lumpectomy and radiation, how is it usually treated? (Mastectomy)	60.2	61.0	58.9	0.66
If 100 women with early breast cancer have a mastectomy, how many will have breast cancer come back in the treated breast area in the 10 years after treatment? (2 to 10%)	37.5	37.9	36.9	0.84
If 100 women with early breast cancer have lumpectomy and radiation, how many will have breast cancer come back in the treated breast in the 10 years after treatment? (5 to 15%)	36.8	41.2	29.8	0.016
Total	52.7	55.7	47.8	0.0002

---

[*] Not all respondents answered all questions.

Table 3

Univariate (Two-Sample t-test or Analysis of Variance) and Multivariable (Linear Regression) Analyses of Factors Associated with Knowledge

			Multivariable	
Characteristic	**Mean knowledge (% correct)**	**Univariate p value**	**Regression coefficient**	**p Value**
Age at diagnosis, y				
< 50	59.1	<0.0001	10.9	<0.0001
>=50*	48.5			
Race				
White	54.6	0.0001	8.4	0.001
Non-white*	43.1			
Education				
< College graduate	46.3	<0.0001	-6.3	0.002
> = College graduate*	56.3			
Annual income				
< $60,000	43.9	<0.0001	-6.7	0.003
>= $60,000*	57.0			
Marital status				
Partnered	54.8	0.004	2.9	0.18
Single/divorced/widowed*	48.1			
Stage				
I	55.2	0.002	4.5	0.02
II*	48.8			
Surgical treatment				
Partial mastectomy	55.7	0.0002	7.7	0.0001
Mastectomy*	47.8			
Site		0.36		
1	50.2			
2	55.1			
3	51.8			
4	53.4			
Months since diagnosis				
< 24	56.4	0.02	5.1	0.01
>= 24*	51.1			

*Referent group.

Table 4

Univariate (t-Test or Chi-Square) and Multivariable Logistic Regression Analyses of Factors Associated with Treatment

	Partial mastectomy[*]	**Mastectomy**[*]	**Univariate**	**Multivariable**	
Factor	**n=272**	**n=111**	**p value**	**Odds ratio of mastectomy**	**95% CI**
Age at diagnosis (% older than 50 y)	66.2	52.3	0.01		
Race (% white)	85.3	80.2	0.22		
Education (% college graduate)	64.7	64.0	0.89		
Marital status (% partnered)	64.7	73.0	0.12		
Annual income (% more than $59,999)	66.9	68.5	0.77		
Stage (% Stage II)	32.7	53.2	0.0002	1.81	0.89, 3.68
Study site (%)			0.83		
1	25.4	23.4			
2	26.5	28.8			
3	24.3	27.0			
4	23.9	20.7			
Importance of: (mean rating on a scale from 0 to 10)					
Keep your breast[*]	6.6[*]	3.0[*]	<0.0001[*]	0.79[*]	0.70, 0.88[*]
Remove your entire breast to gain peace of mind[*]	3.5[*]	9.3[*]	<0.0001[*]	1.88[*]	1.60, 2.20[*]
Avoid cancer coming back in treated breast	9.6	9.9	0.0003		
Avoid having radiation[*]	2.1[*]	5.1[*]	<0.0001[*]	1.23[*]	1.11, 1.36[*]
Avoid the hassle of traditional radiation treatment	2.4	4.4	<0.0001[*]		
Avoid serious side effects of radiation	5.5	6.0	0.21		

Patients who had lumpectomy and then mastectomy were excluded from this analysis.

[*] Factors significant in the final model.

Table 5
Involvement in Decision Making (n=440)

Question about involvement	n	%*	95% CI
Did any of your doctors discuss mastectomy as an option for you?			
Yes	299	68.0	63.4, 72.3
No / I'm not sure	139	31.6	27.3, 36.2
Did any of your doctors discuss lumpectomy and radiation as an option for you?			
Yes	396	90.0	86.8, 92.6
No / I'm not sure	43	9.8	7.2, 12.9
How much did your doctors discuss reasons to have mastectomy with you?			
A lot/Some	237	53.9	49.1, 58.6
A little/Not at all	176	40.0	35.4, 44.7
I am not sure	13	3.0	1.6, 5.0
How much did doctors discuss reasons not to have mastectomy with you?			
A lot/Some	217	49.3	44.6, 54.1
A little/Not at all	195	44.3	39.6, 49.1
I am not sure	18	4.1	2.4, 6.4
How much did doctors discuss reasons to have lumpectomy and radiation with you?			
A lot/Some	332	75.5	71.2, 79.4
A little/Not at all	92	20.9	17.2, 25.0
I am not sure	6	1.4	0.5, 2.9
How much did doctors discuss reasons not to have lumpectomy and radiation with you?			
A lot/Some	159	36.1	31.6, 40.8
A little/Not at all	254	57.7	53.0, 62.4
I am not sure	14	3.2	1.8, 5.3
Did any of your doctors ask you whether you preferred lumpectomy or mastectomy?			
Yes	214	48.6	43.9, 53.4
No	184	41.8	37.2, 46.6
I am not sure	36	8.2	5.8, 11.1

Some questions have been reworded to fit this table.

[*] Not all responses add to 100% due to missing data.