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Prospective Study of Surgical Decision-making Processes for Contralateral Prophylactic Mastectomy in Women with Breast Cancer

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Structured Abstract

Objective—We prospectively examined the psychosocial predictors and the decision-making process regarding contralateral prophylactic mastectomy (CPM) among women with sporadic breast cancer.

Summary Background Data—Increasing numbers of women with breast cancer are seeking CPM. Data are limited about the surgical decision-making process and the psychosocial factors that influence interest in CPM.

Methods—Women with early stage unilateral breast cancer (n=117) were recruited before their first surgical visit at MD Anderson and completed questionnaires assessing knowledge of and interest in CPM and associated psychosocial factors. After the appointment, women and their surgeons completed questions about the extent that various surgical options (including CPM) were

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discussed; also, the women rated their perceived likelihood of having CPM and the surgeons rated the appropriateness of CPM.

Results—Before their first visit, 50% of women were moderately to extremely interested in CPM and 12 (10%) of women had CPM at the time of their primary breast cancer surgery. Less knowledge about breast cancer ($P=0.02$) and greater cancer worry ($P=0.03$) predicted interest in CPM. Greater cancer worry predicted who had CPM ($P=0.02$). Interest in CPM before surgical visit and the likelihood of having CPM after the visit differed ($P < 0.001$). Surgeons' rating of the appropriateness of CPM and the patient's reported likelihood of having CPM were not significantly different ($P=0.49$).

Conclusions—Interest in CPM is common among women with sporadic breast cancer. The informational and emotional aspects of CPM may affect the decision to have CPM and should be addressed when discussing surgical options.

The trend for women with invasive breast cancer to undergo contralateral prophylactic mastectomy (CPM) has been increasing, with U.S. rates over the past decade estimated at 4% to 25%.¹⁻⁵ Although CPM reduces the risk of developing a contralateral breast cancer, it is unclear whether it reduces breast cancer mortality or overall death.⁶⁻⁹ The lack of evidence for a clinical benefit of CPM is particularly relevant for women with sporadic breast cancer, since their annual risk of developing contralateral breast cancer is estimated at 0.5% or lower.¹⁰⁻¹³

Recommendations for interventions aimed towards informed shared decision making for CPM have emphasized the importance of understanding and considering patient psychosocial factors, beliefs and preferences for CPM.¹⁴ Most studies that have investigated psychosocial factors associated with having CPM, however, have included women at high risk of developing breast cancer, such as *BRCA1/2* mutation carriers who have a 40% to 65% lifetime risk of breast cancer and are at greatest risk of contralateral breast cancer.^{9,15-17} For example, in a retrospective study of women with sporadic breast cancer and of women with high-risk breast cancer, reasons for having CPM included the desire to reduce the chances of contralateral breast cancer (98%), to improve survival (94%), and to have peace of mind (95%).¹⁶ Although this study and other retrospective studies have shown overall high satisfaction among women at high-risk who decide to have CPM,^{16,18,19} it is unknown whether these results can be generalized to women with sporadic breast cancer, the largest population of women with breast cancer.

Women with breast cancer often lack sufficient knowledge and information to make informed decisions about treatment.²⁰ How surgeons communicate is an important determinant of women's ultimate treatment decisions and satisfaction.^{21,22} Indeed, factors associated with the decision-making process for CPM have been shown to affect psychosocial outcomes.^{23,24}

An important limitation of studies to date has been the lack of information about the physician-patient communication process regarding the appropriateness of CPM based on the expected benefits and risks²⁵ and the dearth of data focused specifically on women with sporadic breast cancer whose experiences may be quite different than those who are at

higher risk of breast cancer. To the best of our knowledge, this is the first prospective study to examine the psychosocial and communication factors associated with CPM in a population of women with sporadic breast cancer. Based on the existing literature on CPM and on bilateral prophylactic mastectomy in retrospective studies^{15,23,26} and models of decision making,^{27,28} we hypothesized that cognitive and psychosocial factors including the following would influence a woman's decision to have CPM including cancer-specific distress, uncertainty, cancer worry, fear of recurrence, knowledge about breast cancer and CPM, perceived risk, and body image. We also examined the concordance between women's preferences for CPM and their healthcare providers' beliefs about the appropriateness of CPM to determine the opportunities for shared decision-making.

PATIENTS AND METHODS

Eligibility Criteria

Women with newly diagnosed breast cancer were recruited from the Breast Center at The University of Texas MD Anderson Cancer Center (MD Anderson). Inclusion criteria included: stage 0–III unilateral breast cancer; age 18 years or older; and ability to speak, read, and write in English. Women with a previous breast cancer or a history of prophylactic mastectomy, known germline gene mutation for hereditary breast cancer (e.g., *BRCA1*, *BRCA2*, *TP53*) or who were considered high risk based on their family history of breast cancer²⁹ were excluded.

Study Procedures

Participants were recruited before their first surgical visit at MD Anderson and completed screening questions that included information about BRCA testing, family history of breast cancer, and an assessment of their level of interest in having CPM. Eligible participants then completed knowledge and psychosocial measures (see Study Measures). Immediately after the visit, both the women and their breast surgeon completed items about the extent to which surgical procedures, including CPM, were discussed; also, the women rated their perceptions of undergoing CPM, and their surgeons rated the appropriateness of various surgical procedures, including CPM. Women were given \$20 as compensation for their time and effort. The study was approved by the Institutional Review Board at MD Anderson Cancer Center.

Study Measures

Demographic information included age, race/ethnicity, marital status, educational background, employment status, and family history of any type of cancer. Clinical variables that were extracted from medical records included cancer stage, tumor histology, estrogen receptor (ER)/progesterone receptor (PR) status, HER2neu status, type of surgery [segmental mastectomy, unilateral mastectomy or bilateral mastectomy (CPM)], and treatment type (neoadjuvant chemotherapy, adjuvant chemotherapy, radiation therapy).

Cancer-specific distress was measured with the Impact of Events Scale-Revised (IES).³⁰ IES assesses intrusion (intrusively experienced ideas, images, feelings) and avoidance (avoidance of ideas, feelings, or situations), with higher scores indicating more distress.

The Mishel Uncertainty in Illness Scale (MUIS) assessed illness uncertainty.³¹ The MUIS assesses patients' perceptions of uncertainty about their symptoms, diagnoses, treatment, prognosis and has been used with a variety of medical populations including those with cancer.³¹⁻³⁴ The MUIS has four subscales--ambiguity, complexity, lack of information, and unpredictability which can be combined into a single score, with higher scores indicating greater uncertainty.

Breast cancer worry was assessed with a four-item scale developed by Lerman et al.,^{35,36} which assessed the extent to which worry about breast cancer interferes with women's daily functioning. Higher scores indicated more worry.

Fear of recurrence was assessed with a five-item scale that measures beliefs and anxieties about disease recurrence^{37,38} which has been used with a variety of cancer populations and has well-established psychometric properties.^{39,40} Higher scores indicate more fear of recurrence.

Knowledge about breast cancer and treatment was assessed with an 11-item scale.⁴¹ Knowledge about CPM was assessed with five true-false items that were developed by the study team with feedback from other breast surgeons and medical oncologists as well as feedback from several breast cancer patients. Wording was modified to ensure that the items were clear and understandable.

Perception of breast cancer risk was assessed with two items adapted from prior studies.⁴²⁻⁴⁴ Participants estimated their chance of developing a breast cancer recurrence and a new breast cancer in the unaffected breast compared with other women their age (one=much lower to five=much higher).

The Multidimensional Body-Self-Relations Questionnaire--Appearance Evaluation (MBSRQ)⁴⁵ assessed overall satisfaction with one's body and physical appearance. Higher scores on the MBSRQ indicate higher evaluations of overall appearance.

Immediately after the surgical visit, women and surgeons completed items about the extent to which surgical procedures including CPM were discussed (scale of 1=did not discuss to 5=discussed extensively). Surgeons were also asked about the appropriateness of various surgical procedures including CPM for each patient (scale of 1=not at all appropriate to 5=very appropriate) and women were asked about their likelihood of having different surgical procedures including CPM (1=very unlikely to 5=very likely).

Statistical Analysis

Univariate analyses were conducted to determine predictors of initial interest in CPM and having CPM surgery. Wilcoxon rank-sum tests were performed for continuous variables and chi-square or Fisher exact tests were performed on categorical variables for univariate analyses. For the endpoint of having CPM surgery, we examined as predictors, women's ratings of the extent to which CPM was discussed during the surgical visit, the surgeons' ratings of the extent to which CPM was discussed during the visit, women's perceived likelihood of having CPM, as well as the surgeons' perceived appropriateness of CPM for the patient (one to five scale). To avoid excluding variables that might not be directly

associated with outcome variable, but the association might be significant once adjusted for other variables, multivariate logistic regression analysis was performed by first including all variables with p values of <0.10 in univariate analyses. Backward stepwise selection method was then performed by removing the variable with the highest p-value in the multivariable model (least contribution to the model). The multivariable analysis was performed again with remaining variables, and the variable with least contribution to the model was excluded. This process was repeated until all variables remained in the model had a significant p-value (<0.05). Since the goal of this study was to identify variables that were significantly associated with the outcome, rather than building a prediction model, as a common practice, all variables that were insignificantly associated with the outcome variable were excluded. One to five scales were dichotomized with scores of 1–2 indicating little to no discussion, interest, or not very appropriate and 3–5 moderately to extremely discussed, interested or appropriate. We also examined the concordance between women’s interest in CPM before and after the appointment with the surgeon using McNemar’s test of independence. SAS 9.3 (SAS Institute Inc., Cary, NC) was used for data analyses.

RESULTS

A total of 173 women were approached for this study. Of these, 43 were determined to be ineligible (9 non-English speaking, 4 had bilateral breast cancer, 12 had a previous breast cancer and 18 had strong family history of breast cancer or were known carriers of BRCA1/2 gene) and 13 refused to participate due to lack of interest or lack of time. Thus, 117 women (90% participation rate of eligible women) participated in the study from eight different breast surgeon’s clinics with a mean of 14 women recruited per surgeon (range three-21 women). Data from two women were excluded because insufficient information was collected on the baseline psychosocial questionnaire. Mean age was 54 years (range, 24–78 years) (Table 1). Among participants, 67% were Caucasian, 74% were married or living with a partner, 50% had completed college or higher and 58% were employed full- or part-time. Sixty-eight percent reported having a family history of some type of cancer [including breast cancer (women with multiple first degree relatives with breast cancer were not included in this study)]; 18% had ductal carcinoma in situ (DCIS); 26% had stage I, 36% stage II, and 20% stage III disease. Most women (80%) had ER+/PR+ breast cancers and 11% were HER2neu positive. Forty-nine percent had segmental mastectomy, 41% had unilateral mastectomy and 10% had CPM at the time of their primary breast cancer surgery. Fifty-three percent of the women who had unilateral mastectomy had immediate reconstruction and 75% of the women who had CPM had immediate reconstruction.

Before meeting with the breast surgeon, 50% of women indicated being moderately to extremely interested in CPM. After the visit with the surgeon, 43% of women indicated that CPM had been discussed moderately to extensively. After the visit, surgeons indicated that CPM was moderately to extensively discussed in 33% of visits and was not discussed at all in 45% of visits. After the visit with the surgeon, 23% of women indicated that the likelihood of CPM was moderately to extremely likely and 65% reported that CPM was not at all likely. Of the women who went on to have CPM, 84% expressed initial interest in CPM prior to the visit whereas 83% of women who were initially interested in CPM did not

have CPM at the time of their primary breast cancer surgery. Means and standard deviations of psychosocial variables are described in Table 2.

Demographic, knowledge, and psychological factors that were significantly associated with interest in CPM in the univariate analysis included ethnicity ($P=0.04$), cancer worry ($P=0.01$), knowledge about breast cancer ($P=0.03$), and body image ($P=0.03$) (Table 3). In the multivariable model, factors that remained statistically significantly associated with interest in CPM were younger age at diagnosis ($OR=2.77$, $P=0.03$), more cancer worry ($OR=1.23$, $P=0.02$), and less knowledge about breast cancer ($OR=.97$, $P=0.04$) (Table 3).

Factors that were significantly associated with having CPM in univariate analyses were cancer worry ($P=.02$), surgeons' rating of the extent that CPM was discussed ($P=0.01$), women's rating of the extent that CPM was discussed ($P=0.01$) and the women's perceived likelihood of having CPM ($P=0.005$) (Table 4). This finding is expected since sufficient clinical information relevant to the surgical procedure would need to be conveyed to the patient for informed consent. Cancer worry remained statistically significantly associated with having CPM ($P=0.02$) in the multivariable analyses.

There was a significant difference in how much women and their surgeons perceived that CPM was discussed during the visit with women indicating it was discussed more frequently ($P=0.008$). Women's interest in CPM before the surgical visit and their self-reported likelihood of having CPM after the surgical visit differed with fewer women indicating they were likely to have it after the visit ($P < 0.0001$). There was no evidence of discordance between the surgeons' ratings of the appropriateness of CPM and the patient's rated likelihood of having CPM after the surgical visit ($P=0.49$).

DISCUSSION

In our academic medical setting, more than 50% of women with a new diagnosis of sporadic unilateral breast cancer were interested in CPM, and the option of CPM was discussed in about 45% of surgical consultations. Women with more cancer worry and less knowledge about breast cancer were more likely to be interested in CPM when visiting the surgeon for the first time. However, the majority of women did not have CPM as part of their primary treatment for breast cancer and their clinicians' ratings of the appropriateness of CPM may have influenced a woman's likelihood of having CPM. These results demonstrate that there is a significant need during discussions of breast cancer surgical options for clinicians to provide both appropriate education about CPM and to address the psychosocial factors that drive women's preferences for CPM. Since most decision aids for cancer tend to focus primarily on improving knowledge about treatment decisions,⁴⁶ our results also highlight the need to incorporate the emotional and psychosocial aspects in future decision aids designed to improve the decision-making process for CPM.

Our results extend the findings of several retrospective studies that highlight the importance of psychosocial factors such as cancer worry influencing women's decisions about CPM.^{16,47} Importantly, these factors can be addressed and modified. Although studies have generally reported overall satisfaction to be high among women who had CPM, a sizable

number of women report having some regret and/or having worse symptoms than they had expected.^{16,18,23} Finding ways to enhance the decision-making process will likely diminish regrets after surgery. In addition to the key factors we identified in this study, the desire to have CPM is likely driven by other factors including options for reconstruction, other demographic and disease-related factors, previous interactions with other physicians, experiences of family and friends as well as the media and celebrities' well-publicized experiences with prophylactic mastectomy. A desire to "do everything possible" for one's cancer may drive this interest, regardless of whether it is medically or psychologically indicated for a particular woman.

Some limitations of the study should be noted. First, it was conducted at a comprehensive cancer center, where perspectives may differ from those of women receiving treatment in other settings. Also, the sample was primarily non-Hispanic white (68%) so the results may not be generalizable to other racial or ethnic groups. Similar to the results of other studies, race/ethnicity significantly affected CPM rates in our study,^{1,4,48} however, some studies have found no association between race and CPM rates.⁴⁹ Another important caveat to these results is that other factors may have influenced patients' interest or decision to have CPM were not investigated such as method of diagnosis, breast density, insurance coverage or cost, the influence of the media, and CPM among family or friends. The 10% rate of CPM was lower than rates reported at other academic medical centers,⁴⁹⁻⁵¹ and our study was designed to specifically exclude all women with a strong family history of breast cancer or a known genetic predisposition to breast cancer. The observed rate is therefore likely representative of the population of breast cancer patients who choose CPM when the clinical benefit is less certain. Due to the modest number of women in the study who had CPM, the predictors of having CPM should be replicated in larger samples. Importantly, these are surgical decisions made at the time of the primary treatment and women may have considered other surgical procedures including CPM months or even years later.

The etiology of increasing use of CPM in the United States has garnered considerable interest and speculation yet prospective studies in this arena have been limited or non-existent. Our study provides a unique window into the CPM process in that it prospectively describes women's interest in CPM both before and after their visit with the breast surgeon. It also includes the role of health care providers' beliefs in the CPM decision. How surgeons communicate with patients regarding treatment options is an important determinant of patients' ultimate treatment decisions and satisfaction,^{21,22} and studies have shown the importance of surgeons' advice or recommendation in making decisions about CPM.^{18,47} Despite the importance of these conversations for patients, there is little systematic information available to guide these discussions. A more detailed framework based on the current study and examination of these conversations between patients' and healthcare providers' would further elucidate how these decisions are made and provide more guidance on ways to enhance discussions about this important surgical decision. Future studies should also explore the potential impact of individual surgeon's beliefs and practices. The results of this study can be used in the development of evidence-based educational and psychosocial interventions that will enhance decision-making about CPM and improve the quality of life of women with breast cancer.

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Table 1

Baseline Sociodemographic and Clinical Characteristics

Characteristic	Total (N=117)	CPM Interest (Before Visit)		P
		Not at all to a little (N=59)	Moderate to Extremely (N = 58)	
Age (years) [mean (range)]	54.1 (24–78)	55.5 (24–78)	52.5 (28–71)	0.124
Ethnicity				
Caucasian/White	79 (67%)	36 (61%)	43 (74%)	0.039
Hispanic/Latino	16 (14%)	6 (10%)	10 (17%)	
African American/Black	17 (15%)	13 (22%)	4 (7%)	
Asian/Pacific Islander	5 (4%)	4 (7%)	1 (2%)	
Marital status				
Married/Living with Partner	86 (74%)	40 (68%)	46 (81%)	0.112
Single/Divorced/Living Alone	30 (26%)	19 (32%)	11 (19%)	
Educational level				
Less than high school	1 (1%)	0 (0%)	1 (2%)	0.929
High school graduate	56 (49%)	28 (47%)	28 (50%)	
College graduate	45 (39%)	24 (41%)	21 (37%)	
Graduate/professional degree	13 (11%)	7 (12%)	6 (11%)	
Employment status				
Employed full- or part-time	68 (58%)	33 (56%)	35 (61%)	0.105
Unemployed	32 (27%)	14 (24%)	18 (32%)	
Retired	16 (14%)	12 (20%)	4 (7%)	
Stage of disease				
0	21 (18%)	10 (17%)	11 (19%)	0.987
I	30 (26%)	15 (26%)	15 (26%)	
II	42 (36%)	22 (37%)	20 (34%)	
III	24 (20%)	12 (20%)	12 (21%)	
Histology				
DCIS	20 (17%)	10 (17%)	10 (17%)	0.947
Invasive ductal	83 (71%)	41 (70%)	42 (73%)	
Invasive lobular	10 (9%)	6 (10%)	4 (7%)	
Invasive tubular/mucinous	4 (3%)	2 (3%)	2 (3%)	
ER/PR status				
Negative	24 (20%)	13 (22%)	11 (19%)	0.681
Positive	93 (80%)	46 (78%)	47 (81%)	
HERr2neu status				
Negative	46 (39%)	23 (39%)	23 (40%)	0.200
Positive	12 (11%)	9 (15%)	3 (5%)	
Unknown	59 (50%)	27 (46%)	32 (55%)	
Surgery type				
Segmental mastectomy	57 (49%)	32 (54%)	25(43%)	0.045
Unilateral mastectomy	48 (41%)	25 (42%)	23(40%)	

Characteristic	Total (N=117)	CPM Interest (Before Visit)		P
		Not at all to a little (N=59)	Moderate to Extremely (N = 58)	
CPM	12 (10%)	2 (4%)	10(17%)	
Neoadjuvant chemotherapy				
Yes	41 (35%)	18 (30%)	23 (40%)	0.300
No	76 (65%)	41 (70%)	35(60%)	
Adjuvant chemotherapy				
Yes	92 (79%)	44 (76%)	48 (83%)	0.359
No	24 (21%)	14 (24%)	10 (17%)	
Adjuvant radiation				
Yes	74 (65%)	39 (68%)	35 (61%)	0.433
No	40 (35%)	18 (32%)	22 (39%)	

Note: Some totals may not equal 100% due to missing data on individual items

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Table 2

Scores on psychosocial variables at baseline

Variable	Mean	SD	Range
Impact of Events Scale	29.9	15.5	0–69
Uncertainty	70.8	15.9	35–108
Body Image	24	5.2	10–35
General BC Knowledge	74.2	14.2	30–100
CPM Knowledge	2.9	1.3	0–5
Cancer Worry	7.7	2.6	4–13
Fear of Recurrence	64.5	16	20–100
Perceived Risk-Recurrence	3.7	1.6	1–6
Perceived Risk-New Breast Cancer	3.6	1.5	1–6

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Table 3

Univariate and multivariable models for associations between demographic, knowledge, and psychosocial variables and interest in contralateral prophylactic mastectomy (CPM)

Univariate	Interest in CPM			P*
	Low [mean (range)]	High [mean (range)]		
Cancer worry	7 (4 – 13)	8.5 (4 – 13)		0.005
General BC knowledge	77.1 (30 – 100)	71.4 (40 – 100)		0.026
Body image	25.1 (15 – 35)	22.9 (10 – 34)		0.034
Likelihood of having CPM reported by patient (after visit)	1.4 (1 – 5)	2.2 (1 – 5)		0.019
Race [n, %]				0.039
Black	13(76.5%)	4(23.5%)		
Asian/Pacific Islander	4(80%)	1(20%)		
White	35(45.5%)	42(54.5%)		
Hispanic	6(37.5%)	10(62.5%)		
Multivariable	OR	95% CI		p**
age (≤ 50 vs. >50)	2.77	1.08	7.12	0.034
Cancer worry	1.23	1.04	1.46	0.017
General BC knowledge	0.97	0.94	1.00	0.035

Abbreviations: BC (breast cancer), OR (odds ratio), CI (confidence interval)

p* - P-value for Wilcoxon rank sum test or chi-square test

p** - Wald statistics p-value from multivariable logistic regression

Table 4

Univariate and multivariable models for associations between demographic, knowledge, and psychosocial variables and having CPM

Univariate	CPM		P*
	No [mean (std,range)]	Yes [mean (std,range)]	
Cancer worry	7.5 (4 – 13)	10 (4 – 13)	0.0201
Degree of discussion by surgeon	2.2 (1 – 5)	3.3 (1 – 5)	0.0112
Degree of discussion by patient	2.6 (1 – 5)	3.9 (2 – 5)	0.014
Likelihood of having CPM by patient	1.7 (1 – 5)	3.3 (1 – 5)	0.0047
Multivariable	OR	95% CI	P**
Cancer worry	1.38	1.05 – 1.83	0.022

p* - P-value for Wilcoxon rank sum test or chi-square test statistics

p** - Wald statistics p-value from multivariable logistic regression