

The association between patient attitudes and values with strength of consideration for contralateral prophylactic mastectomy in a population-based sample of breast cancer patients

Running head: Factors associated with consideration of CPM

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Author contributions

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Precis: Many breast cancer patients consider contralateral prophylactic mastectomy (CPM), and consideration relates to their decision style and values. Understanding these styles and values could provide an opportunity for improving patient clinician discussions about breast cancer treatment.

ABSTRACT

Background: Little is known about how the individual decision styles and values of breast cancer patients at the time of treatment decision making are associated with consideration of different treatment options, specifically with consideration of contralateral prophylactic mastectomy (CPM).

Methods: We identified newly diagnosed patients with early-stage breast cancer treated in 2013-14, identified through SEER registries of Los Angeles & Georgia, and surveyed them about 7 months after surgery (N=2578, RR=71%). The primary outcome was consideration of CPM (strong vs. less strong). We assessed the association between patients' values and decision styles and strong consideration using multivariable logistic regression.

Results: About one quarter (25%) of women reported strong/very strong consideration of CPM, and another 29% considered it moderately/weakly. Decision styles, including "rational-intuitive" approach to decision making, varied. The factors most valued by women at the time of treatment decision making were: avoiding worry about recurrence (82%), and reducing the need for more surgery (73%). In multivariable analysis, patients who preferred to make their own decisions, those who valued avoiding worry about recurrence, and who valued avoiding radiation significantly ($P<0.05$) more often strongly considered CPM, while those reported being more "logical" and who valued keeping their breast less often did so.

Conclusions: Many patients considered CPM, and consideration was associated with both decision style and values. The variability in decision style and values observed in this study suggests that formally evaluating these characteristics at or prior to the initial treatment encounter could provide an opportunity for improving patient clinician discussions.

Keywords: breast cancer, contralateral prophylactic mastectomy, population-based survey, decision-making, decision styles

INTRODUCTION

The surge in use of contralateral prophylactic mastectomy (CPM) after diagnosis of breast cancer has motivated interest in understanding how the treatment decision-making process can drive patient desire for aggressive procedures that increase morbidity in the absence of a survival benefit. CPM has increased from relatively few among women who do not have an elevated risk of developing a second primary breast cancer to a rate of over 20% in this population and now represents about half of mastectomy performed for breast cancer in the United States.¹⁻³ Importantly, many more women consider getting the procedure than actually receive it.

Remarkably little research has been done to examine the psychological factors that drive patient desire for CPM. Several studies that have examined correlates of the use of CPM have observed that the procedure is received primarily by more highly educated, Caucasian, and insured patients.²⁻⁷ Research that has explored the patient perspective has found women's choices for the procedure to be driven by worry about recurrence and desire for "peace of mind" as well as the desire for better cosmetic outcomes.^{2,5} However, this literature has been limited by a focus on the characteristics of patients who ultimately receive CPM. Indeed, very little is known about all patients who think seriously about receiving CPM, including those who do not ultimately receive it. Surgeons must be able to identify this much broader group of women whose concerns must be addressed as part of the treatment decision making process.

To address this gap in the literature, our study had two objectives. First, we characterized patient perspectives about the importance of different factors related to treatments (values) and underlying attitudes toward decision-making (decision styles) in a large, diverse, population-based sample of patients with early-stage breast cancer at average risk of development of a second primary cancer. Second, we evaluated correlates of strong consideration of CPM, including patient decision style and values.

METHODS

Study Population

The iCanCare Study, a large, diverse, population-based survey study of women with favorable prognosis breast cancer, accrued women ages 20-79 with newly diagnosed breast cancer (DCIS and stages I-II, <5cm in size) as identified by rapid reporting systems from the Surveillance Epidemiology and End Results (SEER) registries of Georgia and Los Angeles County in 2013-2014. Black, Asian, and Hispanic women were oversampled in Los Angeles.⁸ We selected 3,880 of whom 249 women were later deemed ineligible due to having a prior cancer diagnosis or stage III or IV disease; residing outside the SEER registry area; being deceased, too ill or unable to complete a survey in Spanish or English. Of 3,631 eligible women remaining, 1,053 did not return mailed surveys, refused to participate or were lost to follow up. Among the 2,578 respondents (71%), 216 were excluded due to having bilateral disease and/or being a genetic mutation carrier as reported on the survey. The resulting analytic sample was 2,362 women (Supplementary Figure 1).

Data Collection

Patients were sent surveys approximately 2 -3 months after surgery, with median completion time 6-7 months post surgery. We provided a \$20 cash incentive and used a modified Dillman method for patient recruitment.⁹ All materials were sent in English and Spanish to those with Spanish surnames.⁸ Survey responses were then merged with clinical data from SEER. The study was approved by the Institutional Review Boards of the University of Michigan, University of Southern California, and Emory University.

Questionnaire Design and Content

Patient questionnaire content was guided by a conceptual framework, research

questions, and hypotheses. We chose established measures when available and developed new measures when necessary, drawing from the literature and our prior research.¹⁰⁻¹² We used standard techniques to assess content validity, including review by survey design experts, cognitive pre-testing with patients, and pilot studies in selected clinic populations.

Measures

Primary Outcome: Consideration of CPM

We asked women to indicate on a 5-point Likert Scale how much they considered having a mastectomy on their unaffected breast (from not at all to very strongly). We looked at any consideration (weakly, moderately, strongly, or very strongly) vs not at all, as well as categorization into 2 groups: strongly/very strongly vs other groups. For all but our initial descriptive analyses of this variable, we focused on the latter dichotomized comparison.

Key Independent Variables

Decision Style Factors

We used four measures designed to assess women's underlying approach to decision-making (decision-styles) based on prior work.

Decision Making Apprehension Scale: This scale consisted of 4 items, each on a 5-point Likert Scale (not at all to almost always), designed to assess how women normally approach the emotional side of decision-making: a) I worry about making a bad decision, b) I struggle to decide what the right decision is, c) Once I make a decision, I don't look back, and d) I worry a lot about the outcomes of my decisions. The Cronbach alpha for the scale was 0.78 and it formed a single factor with higher scores indicating more decision-making apprehension.

Decision Making Traits: We asked 5 questions to assess the degree to which women indicated they were usually more rational or more intuitive in their approach to general decision-

making based on literature in decision psychology.¹³ The items each had a 4-point Likert-like scale: 1) did you rely on your instincts and feelings or weigh the pros and cons (1 – instincts to 4 – pros and cons); 2) Were you more intuitive or more rational in your thinking? (1-more intuitive to 4- more rational); 3) Did you really think things through or did you go with your first instinct? (1 – went with my first instinct to 4- thought things through); and 4) Did you spend a lot of time reviewing the details or did you make decisions quickly? (1- quick decisions to 4-review details), and 5) Did you do what seemed most logical or did you just follow your heart? (1- follow heart to 4-more logical). Each of these items was dichotomized.

Decision Autonomy Preference: We asked 2 questions to assess desired role in decision-making. They were asked to indicate the degree they wanted their doctor to tell them what to do, and the degree to which they preferred to make their own breast cancer treatment decisions, each on 5-pt scale from not at all to all the time. Each was categorized into (quite a bit/all the time) vs less.¹⁴

Patient Values

We assessed the women's reports of the importance of sixteen underlying values related to breast cancer treatment. For each value, we asked women to indicate how important it was to her at the time of making her treatment decision on a 5-point Likert Scale (from not at all to very important). For analysis, an indicator was created for reporting "very" or "quite" important vs. other categories.

Covariates

Covariates used in this analysis included patient demographics obtained from the patient questionnaire. We included age, race/ethnicity (White, Black, Latina, Asian, Other/Unknown), educational attainment (high school graduate or less, some college or more), marital status (married/partnered vs. not), income group (<40K, 40-<90K, >90K), insurance status (Private, Medicare, Medicaid, other, none), bra cup size (A/B, C, D, DD+) and family history of breast

cancer (none vs. 1 or more first degree relatives). We also included whether the patient reported having had an MRI (yes/no/missing). Stage (0, I, II) was collected from SEER. An indicator of high risk for having a genetic mutation was created from both patient report and SEER variables, as described in other work.³ Geographic site (GA or LA) was also included to account for regional differences.

Statistical Analyses

We first calculated the proportion of women who considered CPM strongly or very strongly (hereafter referred to as “strong consideration”) overall, and by all demographic and clinical factors, including risk status. We generated descriptive statistics of each decision style measure, and for all 16 values overall, by generating the proportion indicating quite/very important for each value. We then evaluated associations between these measures and strong consideration of CPM after adjusting for the covariates noted above.

Multivariable logistic regression was used to explore correlates of strong consideration of CPM, including decision style factors, values and covariates that remained significant at $P < 0.05$ in the adjusted analyses. Parsimonious multivariable models were constructed using backward selection techniques using a three step approach. First decision style factors and values were modeled separately each along with all demographic and clinical factors to determine important decision style factors and values. Second, significant decision style and values from each model were then modeled simultaneously again retaining all demographic and clinical factors. Finally, significant decision style factors, values, demographic and clinical factors were retained to arrive at the final parsimonious model. This model was adjusted for clustering at the surgeon level to account for potential surgeon-level practice attributes that may impact patients’ consideration of CPM, such as the availability of or propensity to refer to reconstructive surgeons.¹⁵⁻¹⁷

All statistical analyses incorporated weights to account for differential probabilities of sample selection and non-response. Survey and SEER item non-response was low (<5%) for

all covariates. We compared the distributions between non-respondents and respondents for age, race, stage and site. White patients (vs. minorities) and those with stage I cancer (vs. stage II) were significantly more likely to respond, which was then addressed by weighting to ensure that the analyses were representative of the original population.

To correct for the potential of bias due to missing data, values for missing items were imputed using sequential multiple imputation (SMI).^{18,19} Five multiply imputed datasets were analyzed and model estimates combined to account for additional uncertainty due to imputation. Results were compared between SMI analyses and complete-case analyses for any meaningful differences. Odds ratios (OR) with 95% confidence intervals (CI) are reported for models, with p-values ≤ 0.05 considered significant. All analyses were performed using SAS version 9.4 (Cary, NC).

Results

Sample Characteristics

The characteristics of the sample overall and by degree of consideration of CPM are provided in Table 1. Mean age was 62 (SD 11) years. Overall, 25% of patients had DCIS, 47% Stage I disease, and 25% Stage II disease. Slightly over half were White (54%); 430 (18%) were Black, 413 (14%) Latina, and 205 (9%) Asian. Most had some college or more educational attainment (72%). The majority (1260, 54%) had private insurance, but 682 (29%) had Medicaid and 328 (13%) Medicare. A quarter (24%) reported having a first-degree family member with breast cancer. Most (71%) were not at high risk for a second primary breast cancer.

Overall, about one quarter (25%) of women reported strong or very strong consideration of CPM, and another 29% considered it moderately or weakly. Of those who considered it strongly, 13% received unilateral mastectomy and 16% breast conservation. In bivariate

analyses, women who considered CPM strongly/very strongly were younger, more educated, white, had private insurance, and had a family history of breast cancer, and more often from Georgia.

TABLE 1

Decision styles

The mean score on the decision apprehension scale was 2.5 (range 1-5, from not very to very apprehensive). More than half of respondents reported that they were more rational than intuitive (75%), more often thought through decisions than went with their instinct (78%), more often reviewed details than made quick decisions (61%), and were more logical than following their heart (83%) in their approach to treatment decision-making. Over half (59%) indicated they wanted their doctor to tell them what to do quite/all the time, and just over one third (37%) reported that they preferred to make their own decisions quite a bit/all the time.

Values

There was considerable variation in the factors valued by patients in making treatment decisions. Figure 1 shows the % of patients who indicated each value or value group was “very or quite important” to them in making their treatment decision. The most common value women reported being quite/very important was allowing them to avoid worry about the cancer coming back (82%), followed by reducing the need for more surgery (73%), being the newest, most advanced treatment (69%), and avoiding treatment side effects (67%). The least commonly reported to be quite/very important was to have the same treatments as other women had received (23%).

Factors associated with Strong/Very Strong Consideration of CPM

Table 2 shows the odds ratios for associations between individual decision style and values and strong consideration of CPM, after adjustment for the patient demographic and disease characteristics in separate regression models. Having higher levels of decision apprehension was modestly associated with strong consideration (OR: 1.14; 95% CI 0.99-1.31), while women who reported more logical approaches to decision-making were less likely to have strong considered CPM (OR: 0.52; 95% CI 0.31-0.71). Women who preferred their doctor make the decision less often strongly considered CPM (OR: 0.69; 95% CI 0.55-0.87), while women who preferred to make their own treatment decisions more often strongly considered CPM (OR: 1.74; 95% CI 1.39-2.18). Several values were significantly associated ($P < 0.01$) with strong consideration of CPM, including women who said the following were quite/very important at the time of treatment decision making: avoiding worry about the cancer coming back, avoiding exposure to radiation, requiring fewer trips back and forth for treatment, and choosing treatments that were most extensive. Conversely, women who said that choosing treatments that were least extensive, allowed them to keep their natural breast, were the same treatments as other women had were significantly ($P < 0.001$) less likely to strongly consider CPM.

Table 2

Figure 2 displays a forest plot showing the multivariable parsimonious logistic regression results for strong consideration of CPM, adjusted for clustering at surgeon level. Patients who had a family history of breast cancer and a larger breast cup size had higher odds of strong consideration of CPM than their counterparts (OR: 2.19; 95% CI 1.65-2.91, OR 1.76; 95% CI 1.17-2.65, respectively), while those from Georgia had lower odds (OR: 0.60; 95%CI 0.42-0.85). Latina women also reported strong consideration of CPM more often than white women (OR:

2.14; 95% CI 1.37-3.34), while African American women reported strong consideration of CPM less often than white women (OR: 0.63; 95% CI 0.43-0.93). Two decision styles remained significantly associated with strong consideration of CPM in the multivariable model: women who preferred to make their own treatment decisions more often strongly considered CPM (OR: 1.56; 95% CI 1.21-2.01), while women who reported being “more logical” in their decision making less often strongly considered CPM than those who reported “following their heart” (OR: 0.50; 95% CI 0.34-0.72). Three values remained significant: avoiding worry about the cancer coming back (OR: 2.26; 95% CI 1.40-3.66), avoiding radiation exposure (OR: 2.85; 95% CI 2.19-3.68) were both associated with strong consideration, while allowing you to keep your natural breast was significantly and inversely associated with strong consideration of CPM (OR: 0.12; 95% 0.08-0.17)

DISCUSSION

In this large, diverse, population-based sample of newly diagnosed breast cancer patients with favorable prognosis, we found considerable variation in both the manner with which patients reported approaching treatment decision making (decision styles) as well as in what women valued at the time of treatment decision making; while most strongly valued avoiding worry about the cancer coming back, other factors were also important to many women. We further found that nearly a quarter of women strongly or very strongly considered having their unaffected breasts removed as part of treatment for their breast cancer, and another 29% considered it moderately or weakly. Our study contributes to the literature about the rise in CPM by deconstructing the decision-making process. Prior to receipt of CPM, all patients must move through a process of weighting the treatment options and consider how the procedure aligns with their values. Factors associated with consideration, particularly strong consideration, are potentially actionable targets for education and intervention.

Importantly, our results suggest that “values” matter slightly more than underlying personality traits in determining who strongly considers this procedure, though some decision styles were relevant. Our measure of decisional apprehension—developed to assess the type of person who may be more likely to make a decision for extensive treatment to avoid regretting it later—was notably not significantly associated with strong consideration when other factors were included in our model. Similarly, while most of the “rational-intuitive” items were not associated with strong consideration, women who endorsed being more logical in their decision-making *less often* strongly considered this procedure. This held even when controlling for educational status, further underscoring the importance of this finding across all types of patients. This finding further suggests that having a better understanding a woman’s underlying approach—logical vs. more emotional (i.e., “going with the gut”)—may provide opportunities for individualizing the approach to education about risks and benefits.

We also found that women who reported desiring to play a more active role in decision-making more often strongly considered CPM. This finding is consistent with prior work showing that more involved patients, those who report making patient-driven decisions rather than shared or surgeon-driven decisions, more often chose mastectomy, at a time when CPM was not a widely performed procedure.^{10,11} Our current result confirms that such patient-led decision-making is also associated with consideration of even more extensive surgery than unilateral mastectomy. These findings call into question the notion that simply involving patients in decision making is likely to translate to less overtreatment²⁰. They further suggest that perhaps we need to refocus efforts on targeting patients who desire considerable control in the decision making process, as well as on aspects of decision-making that are not purely rational. The importance of affect in general decision-making has been identified,^{21,22} and highlighted in the seminal work by Kahneman.²³ Our findings support that educational efforts in breast cancer treatment should address the intuitive or affective reaction patients have to the meaning of the diagnosis and the prospects of the arduous treatment course, as well as the cognitive, aspects

of decision-making. For instance, recognizing that it is not uncommon for patients to have activated intuitive/affective rather than rational pathways of decision-making, a common psychological shortcut or heuristic.^{23,24} This may require interventions using methods targeted to this end such as providing patient stories, as well as numerical information, to appeal to the emotional nature of this decision.

Several of the values measured in our study were associated with strong consideration in the anticipated direction when adjusting for patient and disease characteristics. When women valued things that would align with receiving more treatment, such as avoiding worry about recurrence, and choosing treatments that were more extensive, they more often strongly considered CPM. Conversely we also found that when women valued things that would align with less surgery, such as keeping their natural breast or choosing treatments that were less extensive, they less often strongly considered CPM.

The importance of these values, which have been identified in prior studies, reinforces the need to address directly patients perceptions of risk of recurrence and their reactions to it,²⁵ as many patients overestimate their actual risk of recurrence following treatment. Furthermore, prior work by our team has shown an association between worry about recurrence and subsequent receipt of CPM.⁴ This is particularly concerning given that CPM does not confer benefit for reducing recurrence risk or on long term survival in the population studied in this analysis (non BRAC1/2 positive, no strong family history of breast or ovarian cancer).²⁶⁻²⁸ Our current finding, that worry is associated with consideration as well as utilization, suggests interventions at the time women are considering their treatment options may be useful. Furthermore, the powerful desire for many patients to avoid radiation motivates the need to ensure they are well educated about the benefits and risks of treatment options that include this modality as an adjuvant.

Aspects of this study merit comment. Strengths of this study include a large, diverse sample, high participation rate, and use of unique patient reported measures. However, the

study has some limitations. Patients lived in two geographic regions, so may not represent all U.S. breast cancer patients. . We did not have details on some practice factors that might have influenced patients desire for CPM such as information and availability of breast reconstruction options. However, we did control for clustering by surgeon and geographic locations. Finally, associations observed in the study are not necessarily causal.

IMPLICATIONS

Our results have important implications for patient-clinician communication to support individualized treatment decision-making. Many more patients consider having CPM, even in the absence of potential for survival benefit, than actually receive it. Assessing decision style and values of patients at or prior to the initial treatment encounter could provide an opportunity for improving deliberation by tailoring discussion about treatment options to embrace the patient's own style and values. There is a need to better educate patients about misperceptions associated with their values; for instance ensuring they understand the actual risk of recurrence since that value is associated with consideration of more extensive treatment. Our results suggest these are key areas for intervention, even in the context of quality improvement or other initiatives to ensure appropriate use of treatments. These assessments can further help physicians to tailor communications to better target patients who may not wish to defer to physicians and/or those who are engaged in more intuitive than rational decision processes.

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Figure Legends:

Figure 1: Patient values in breast cancer treatment decision making

Figure 2: Adjusted Associations (Odd Ratios) from Multivariate Model Explaining Patients' Strong Consideration of CPM adjusted for clustering at the surgeon level

Supplementary Figure 1: Study Flow Diagram

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Characteristic	Total (N)	Weighted % or Weighted Mean (SD)	% Strongly Considered
Age at Time of Survey (years)			
Mean age	2,632	61.8 (10.9)	56.4 (11.0)
Study Site			
Georgia	1244	53.9	28.3
Los Angeles County	1118	46.1	19.2
Race/Ethnicity			
White	1273	57.2	25.7
Black	422	18.0	19.4
Hispanic	402	13.6	26.8
Asian	204	8.7	19.3
Other/Unknown/Missing	61	2.5	22.4
Education			
At least some college	1658	71.9	26.3
High school graduate or less	679	27.1	17.7
Missing	25	1.0	33.4
Marital Status			
Married/partnered	1474	62.7	26.1
Not married	859	36.0	20.7
Missing	29	1.3	22.5
Income (annual)			
Less than \$40,000	719	29.3	21.5
\$40,000 - <\$90,000	649	28.3	25.8
\$90,000 or more	579	25.8	28.9
Missing	415	16.6	18.2
Insurance			
Private	1239	53.6	30.3
Other public	30	1.2	25.2
Medicare	672	28.7	14.3
Medicaid	319	12.6	20.7
None	11	0.5	28.0
Missing	91	3.5	20.6

Table 1 Patient Demographic and Clinical Characteristics (n=2362)			
Characteristic	Total (N)	Weighted % or Weighted Mean (SD)	% Strongly Considered
Cancer Stage			
0 - DCIS	425	25.2	23.1
I	1238	46.8	22.9
II	598	24.6	26.8
Missing	101	3.4	27.5
High Risk (for 2nd primary cancer)			
Yes	636	27.3	33.8
No	1668	70.7	20.5
Not known	58	1.9	18.2
Family history breast cancer			
Yes	536	23.4	30.1
No	1650	69.2	21.9
Missing	176	7.4	25.6
Breast Cup Size			
A/B	750	31.9	22.8
C	730	31.0	21.7
D	473	19.7	24.0
DD and greater	339	14.5	31.4
Missing	70	3.0	27.2
MRI			
Yes	1391	59.1	26.7
No	765	32.9	20.2
Missing	206	8.1	20.9

Table 2. Association of decision style and values variables individually with strong consideration of CPM adjusting for covariates*		
	OR (95% CI)	P value
Decision Styles		
Decision apprehension scale	1.14 (0.99-1.31)	0.080.
Rational vs. intuitive	1.18 (0.89-1.57)	0.24
Think through vs. first instinct	0.91 (0.68-1.21)	0.48
Review in detail vs. quick decisions	1.09 (0.86-1.37)	0.52
Logical vs. follow your heart	0.52 (0.37-0.71)	<0.001
Prefer to make own decisions (all/most of time vs. less)	1.74 (1.39-2.18)	<0.001
Values		
Avoid worry about cancer coming back	2.27 (1.54-3.35)	<0.001
Reduce the need for more surgery	0.92 (0.71-1.20)	0.54
Avoid side effects of treatment	1.23 (0.96-1.58)	0.10
Avoid exposure to radiation	2.59 (2.03-3.30)	<0.001
Require fewer trips back and forth for treatment	1.51 (1.18-1.92)	<0.01
Did not make you feel bad about your body	1.25 (0.99-1.57)	0.05
Were most extensive possible	1.45 (1.10-1.92)	<0.01
Were least extensive possible	0.70 (0.55-0.91)	<0.01
Allowed you to keep natural breast	0.15 (0.12-0.21)	<0.001
Were the same treatments other women received	0.63 (0.46-0.86)	<0.01
Were the newest most advanced treatments	0.82 (0.64-1.06)	0.13
Had the shortest recovery time	0.77 (0.61-0.97)	0.02
Did not require you to spend a lot of your own money	0.85 (0.67-1.09)	0.20
* adjusted for all covariates included in table 1		

Figure 1. Patient values in breast cancer treatment decision making

When making your treatment decision, how important was it that the treatment(s).....

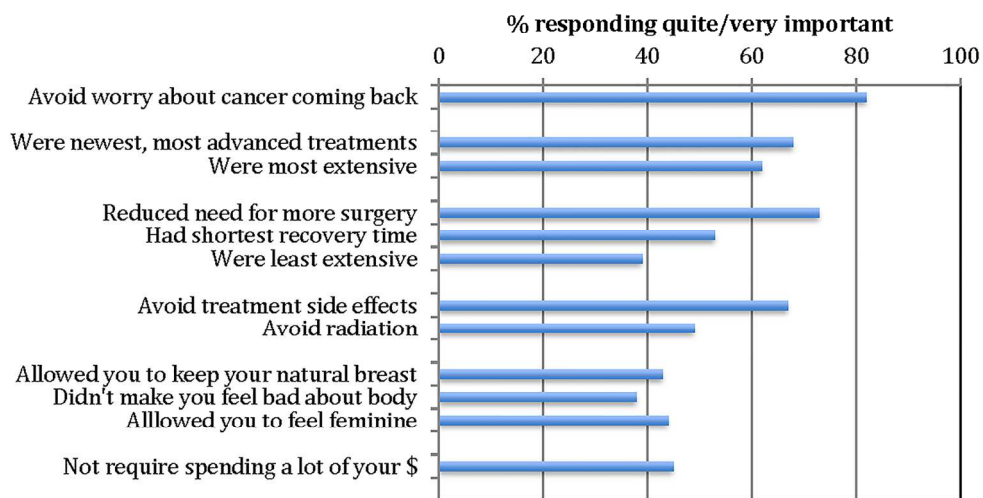


Figure 1: Patient values in breast cancer treatment decision making

171x134mm (300 x 300 DPI)

Accepted

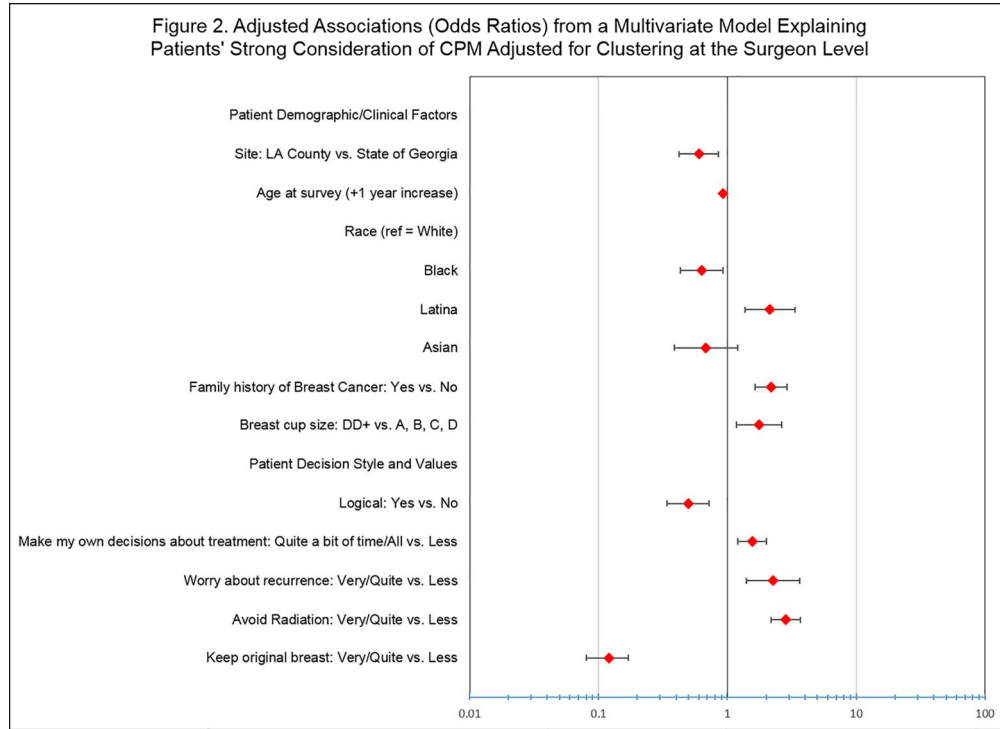
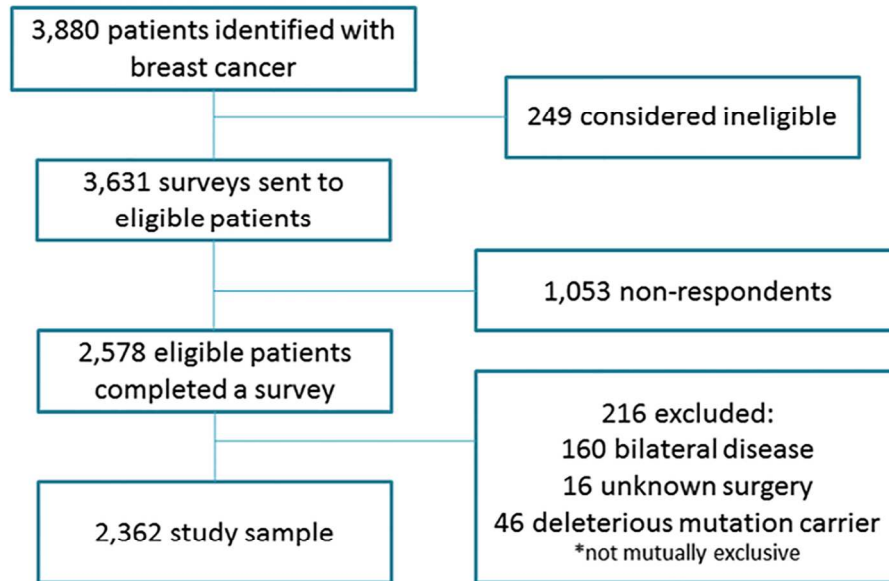


Figure 2: Adjusted Associations (Odd Ratios) from Multivariate Model Explaining Patients' Strong Consideration of CPM adjusted for clustering at the surgeon level

127x92mm (300 x 300 DPI)

Accep

Supplemental Figure: Study Flow Diagram



Supplementary Figure: Study Flow Diagram

171x128mm (300 x 300 DPI)

Accep

Section B: Diagnosis and Testing of Your Cancer

Genetic Testing for Cancer Risk

Genetic testing for cancer risk – often called BRCA tests or multi-gene panel tests – looks for gene mutations or changes to see if women and their families have a greater risk of developing breast cancer in the future.

B15. Genetic tests for breast cancer risk are ordered by a doctor or genetic counselor and can be done with either a blood test or a saliva test where you rinse your mouth with mouthwash and spit into a tube.

Have you **ever** had a blood or saliva genetic test for breast cancer risk that was ordered by a doctor or genetic counselor?

Yes No Don't know

B15a. Why haven't you had a genetic test for breast cancer risk?
Please mark ALL that apply.

- I plan to have a genetic test in the future
- I don't know if I've had a genetic test
- My doctor didn't recommend it
- I didn't want it
- My family didn't want me to get it
- It was too expensive
- I was afraid I would lose my insurance or have to pay more for insurance
- I was afraid of discrimination
- Other (please explain): _____

Please go to B22 "Tumor Tests" on page 7

B16. Why did you get a genetic test? **Please mark ALL that apply.**

- My doctor thought I should
- My family wanted me to be tested
- I wanted to get more information about my own health
- I wanted to get more information for my family members
- Because of my family history
- To help me decide about my treatment
- Other (please explain): _____

Please continue to B17 at the top of the next page

If you have NOT had a genetic test for breast cancer risk, please skip this page and go to B22 →

B17. When did you have the genetic test?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Before I was diagnosed with breast cancer	After I was diagnosed but before I had surgery	After I had surgery to treat my breast cancer

B18. What was the result of the genetic test? **Please mark ONE.**

- I did not have any mutations in the gene tests
- I had a mutation in the BRCA1 or BRCA2 gene that increases the risk of breast cancer
- I had a mutation in another gene (not BRCA1 or BRCA2) that increases the risk of breast cancer
- A gene change was found, but not one that has been shown to increase the risk of breast cancer (sometimes called a “variant of uncertain significance”)
- I don’t know the results
- Other (please explain): -----

B21. Did the genetic test results influence your decision about whether or not to have **both breasts** removed?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was <u>never</u> <u>interested</u> in having both breasts removed	Made me <u>much less</u> interested	Made me <u>less</u> interested	Did not influence my decision	Made me <u>more</u> interested	Made me <u>much more</u> interested

Section C: Your Treatments

Surgery

C2. What was the first surgery that you had to remove your breast cancer after the biopsy test?

- I did not have any surgery after the biopsy
- I had a mastectomy (removal of the entire breast)
- I had a lumpectomy (removal of the cancer and some surrounding tissue)

Please go to C3 at the top of the next page

a. Did you have a second lumpectomy to remove more breast tissue from the same breast?

- Yes – I had another lumpectomy to remove more breast tissue from the same breast
- No – I only had one lumpectomy

b. Did you have a mastectomy later, on the same breast?

- Yes – I had a mastectomy after my lumpectomy
- No – I did not have a mastectomy

c. How strongly did your doctor recommend that you have a mastectomy after your initial lumpectomy?

- Very strongly Strongly Moderately Weakly Not at all

d. How strongly did you request to have a mastectomy after your initial lumpectomy?

- Very strongly Strongly Moderately Weakly Not at all

Please continue to C3 on the next page

C3. What kind of mastectomy did you have?

- I did not have a mastectomy
- Mastectomy only – no reconstruction
- Mastectomy with reconstruction and I kept my own nipple, called a nipple sparing or nipple saving mastectomy
- Mastectomy with reconstruction and my original nipple was removed

C4. What type of breast reconstruction did you have?

- I have not had any breast reconstruction surgery
- A DIEP flap, TRAM flap, or latissimus dorsi flap (uses your own tissue from the abdomen or back)
- An implant (silicone or saline)
- Other (please explain): _____

C5. Did you have a mastectomy on **both breasts**?

<input type="radio"/> Yes	<input type="radio"/> No
------------------------------	-----------------------------

Go to C6
below

Please go to C7 at the
top of the next page

C6. How important were the following factors in your decision to have a mastectomy on **both breasts**?

	Not at all important	A little important	Somewhat important	Quite important	Very important
a. My age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Having a family history of breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Wanting both breasts to match after reconstruction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section D: Decision Making

D1. **In general**, please tell us how often you have these thoughts and feelings when you make decisions.

	Never	Rarely	Sometimes	Often	Always
a. I worry about making a bad decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I struggle to decide what the right decision is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I get angry at myself when I have made a bad decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I worry a lot about the outcomes of my decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D2. When making decisions about **how to treat my breast cancer**...

	Not at all	A little	Somewhat	Quite a bit	A lot
a. I weighed the pros and cons of all the treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I feel like I really thought through all the issues important to the treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I talked with others – family or friends – before making treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I talked with other breast cancer patients before making treatment decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I spent time thinking about all of the treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D3. When making decisions about **how to treat my breast cancer**...

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I would like to have had more information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I would like to have participated more	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I am satisfied with the amount of time I had	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I am satisfied with the amount of involvement I had from family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D4. **When decisions were being made about your treatments**, how important was it to you that your treatments...

	Not at all important	A little important	Somewhat important	Quite important	Very important
a. Reduced the need for more surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Allowed you to avoid side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Allowed you to avoid exposure to radiation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Required fewer trips back and forth for treatment visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Did not make you feel bad about your body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Kept you from worrying about the cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Allowed you to feel feminine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Were the most extensive possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Were the least extensive possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Allowed you to keep your original breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Were what your partner/family wanted you to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Were what your doctor wanted you to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. Were the same treatments that other women you know have received	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. Were the newest, most advanced treatments available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o. Had the shortest recovery time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p. Gave you peace of mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q. Allowed you to avoid having follow-up mammograms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
r. Did not require you to spend a lot of your own money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
s. Had a lower possibility of complications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
t. Allowed you to continue to care for your home and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
u. Allowed you to continue to work for pay	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D5. At the time that decisions were being made about your treatments, how much do you feel that your preferences were considered?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	Slightly	Moderately	Very much	Completely

Surgery decisions

D6. When did you make a decision about your initial surgical treatment?

- Before my first visit with a surgeon
- After my first visit with a surgeon
- After two or more visits

D7. Did you see a second surgeon for an opinion about your surgery treatment options?

Yes

a. Did that second surgeon perform your breast surgery?

- Yes No

No

D8. How strongly did the surgeons you consulted for breast cancer recommend one option over the other for your initial surgery?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly recommended <u>lumpectomy</u>	Weakly recommended <u>lumpectomy</u>	Did not recommend one surgery option over the other	Weakly recommended <u>mastectomy</u>	Strongly recommended <u>mastectomy</u>

D9. How strongly did you consider having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very strongly	Strongly	Moderately	Weakly	Not at all

D10. When you discussed treatment options with your surgeon, was the idea of having a mastectomy on both breasts ever discussed? **Please mark ONE.**

- No, it was never discussed
- Yes, and I was the first to bring it up
- Yes, and my surgeon was the first to bring it up
- Yes, and another person I brought to my clinic visit was the first to bring it up

D11. How much time did you spend talking with the surgeons you consulted for breast cancer about having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No time at all	A little bit of time	Some time	Quite a lot of time	All of the time (it was the only option we talked about)

D12. How strongly did the surgeons you consulted for breast cancer recommend having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strongly recommended it	Weakly recommended it	Did not make a recommendation – left it up to me	Weakly recommended <u>against</u> it	Strongly recommended <u>against</u> it

D13. How much did the surgeons you consulted for breast cancer oppose your interest in having a mastectomy on both breasts?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all	A little bit	Somewhat	Quite a bit	Very much	I did not have any interest in having a mastectomy on both breasts

D14. My surgeons told me that having a mastectomy on my “other” breast – the breast without cancer – would:

	Yes	No	Not discussed
a. Give me a better chance of surviving the breast cancer I already have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Reduce the chances of the breast cancer I already have coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Reduce the chances of developing a new cancer in my “other” breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Improve the cosmetic outcome of my surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Make my recovery from the surgery take longer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section J – Family History of Cancer

To help us better understand your family history, please answer the following question to tell us if any of your blood relatives have had breast cancer and how old they were at the time of their breast cancer diagnosis.

J1. Has your mother ever been diagnosed with breast cancer?

- Yes, my mother was diagnosed with breast cancer before age 50
- Yes, my mother was diagnosed with breast cancer at or after age 50
- No
- Don't know

Sisters

J2. How many sisters do you have? 0 1 2 3 4 or more

J3. How many of your sisters have been diagnosed with breast cancer? 0 1 2 3 4 or more

J4. Have any of your sisters been diagnosed with breast cancer before age 50? Yes No Don't know

Daughters

J5. How many daughters do you have? 0 1 2 3 4 or more

J6. How many of your daughters have been diagnosed with breast cancer? 0 1 2 3 4 or more

J7. Have any of your daughters been diagnosed with breast cancer before age 50? Yes No Don't know

J8. Although it is uncommon, men can also get breast cancer. Has a man in your family (blood relative) ever been diagnosed with breast cancer?

- | | | |
|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Yes | No | Don't know |

J9. Have any of your parents, brothers, sisters, or biological (blood related) children ever been diagnosed with any of the cancers below? **Please mark ALL that apply.**

- | | | | | |
|-----------------------------------------|--------------------------------------|------------------------------------------------|---------------------------------------------|-------------------------------------------------|
| <input type="radio"/> Ovarian cancer | <input type="radio"/> Uterine cancer | <input type="radio"/> Prostate cancer | <input type="radio"/> Colon cancer | <input type="radio"/> Stomach (gastric) cancer |
| <input type="radio"/> Pancreatic cancer | <input type="radio"/> Brain cancer | <input type="radio"/> Sarcoma (muscle or bone) | <input type="radio"/> Ocular melanoma (eye) | <input type="radio"/> Cutaneous melanoma (skin) |
| <input type="radio"/> Leukemia (blood) | <input type="radio"/> None of these | | | |

Section K: Home and Work

K5. **At the time of your breast cancer diagnosis**, what was the total yearly income of your entire household, before taxes, from all sources – including child support, alimony, disability, social security, and unemployment?

- Less than \$5,000
- \$5,000-\$9,999
- \$10,000-\$19,999
- \$20,000-\$29,999
- \$30,000-\$39,999
- \$40,000-\$59,999
- \$60,000-\$89,999
- \$90,000 or more
- Don't know

Current Status

K21. Which of the following best describes your **current** employment status? **Please mark ALL that apply.**

- Employed full-time
- Employed part-time
- Unemployed and looking for work
- Temporarily laid off or on sick or other leave
- Disabled
- Retired
- Student
- Homemaker
- Other (please explain): _____

K22. Please tell us about your medical insurance right before you were diagnosed with breast cancer as well as your medical insurance at the present time. **Please mark ALL that apply in both columns.**

What type of medical insurance...

	Did you have right before your breast cancer diagnosis?	Do you currently have?
a. None	<input type="radio"/>	<input type="radio"/>
b. Insurance provided through my current or former employer or union (including HMO)	<input type="radio"/>	<input type="radio"/>
c. Insurance provided to another family member (e.g., spouse) through their current or former employer or union (including HMO)	<input type="radio"/>	<input type="radio"/>
d. Insurance purchased directly from an insurance company (by you or another family member)	<input type="radio"/>	<input type="radio"/>
e. Insurance purchased from an exchange (sometimes called "Obamacare" or the Affordable Care Act)	<input type="radio"/>	<input type="radio"/>
f. Medicaid or other state provided insurance	<input type="radio"/>	<input type="radio"/>

g. Medicare/government insurance	<input type="radio"/>	<input type="radio"/>
h. Veterans Affairs (VA, including those who have ever used or enrolled for VA health care)	<input type="radio"/>	<input type="radio"/>
i. Other (please explain): _____	<input type="radio"/>	<input type="radio"/>

Section M: A Few More Questions

M1. Today's date is: _____ / _____ / _____
month day year

M2. About how tall are you? _____ feet _____ inches or _____ meters

M3. **At the time of your breast cancer diagnosis**, about how much did you weigh?

_____ pounds or _____ kilograms

M4. **Before your breast surgery**, what was your bra cup size?

- A D
 B DD
 C Other (please explain): _____

M5. **In the 12 months before your diagnosis with breast cancer**, what was your experience with your menstrual periods?

- I had no menstrual periods in the 12 months before my breast cancer diagnosis
 I had regular (or the usual timing of) menstrual periods in the 12 months before my breast cancer diagnosis
 I had a change in the timing of menstrual periods in the 12 months before my breast cancer diagnosis

M6. **In the 12 months before your breast cancer diagnosis**, did you experience hot flashes or night sweats at any time – even once?

- Yes No

M7. What is your birth date? _____ / _____ / _____
 month day year

M8. When you were diagnosed with breast cancer, what was your marital status?

- Married Living with partner
 Divorced Widowed
 Separated Never married

M9. What is the highest level of education you have completed?

- No high school Some college or technical school
 Some high school College graduate (Bachelor's degree)
 High school graduate or G.E.D. Graduate degree or higher

M10. Are you of Hispanic, Latino, or Spanish origin?

- Yes, Mexican, Mexican-American, or Chicano
 Yes, Puerto Rican
 Yes, Cuban
 Yes, another Hispanic, Latino, or Spanish origin (please explain): _____
 No

M11. Are you of Jewish descent?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes	No	Don't know

M12. For how many years have you lived in the United States? _____ years

M13. In what country were you born? _____

- Don't know

M14. In what country was your mother born? -----

Don't know

M15. In what country was your father born? -----

Don't know

M16. Which of the following best describes your race? **Please mark ALL that apply.**

White

Chinese

Black or African-American

Filipino

American Indian or Alaska Native

Japanese

Native Hawaiian or other Pacific Islander

Korean

Asian Indian

Vietnamese

Other Asian (please explain): -----

Other Race (please explain): -----