

Treatment decisions and the employment of breast cancer patients: results of a population-based survey

Running head: Employment of breast cancer patients

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Precis: Working patients with early-stage breast cancer who received more aggressive treatments were more likely to experience substantial employment disruptions. Information regarding the impact of treatment decisions on employment is relevant for patient decision-making.

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ABSTRACT

Background: Many patients with breast cancer work for pay at time of diagnosis, and the treatment plan may threaten their livelihood. Understanding work experiences in a contemporary population-based sample is necessary to inform initiatives to reduce the burden of cancer care.

Methods: We surveyed women aged 20-79 years diagnosed with stages 0-II breast cancer as reported to the Georgia and Los Angeles SEER registries in 2014-15. Of 3672 eligible women, 2502 responded (68%); we analyzed 1006 who reported working before diagnosis.

Multivariable models evaluated correlates of missing >1 month and stopping work altogether vs missing ≤ 1 month.

Results: In this diverse sample, most patients (62%) received lumpectomy; 16% had unilateral mastectomy (8% with reconstruction); 23% had bilateral mastectomy (19% with reconstruction).

One third (33%) received chemotherapy. Most (84%) worked full-time before diagnosis, but only 50% had paid sick leave, 39% disability benefits, and 38% flexible work schedules.

Surgical treatment was strongly correlated with missing >1 month of work (OR 7.8 for bilateral mastectomy with reconstruction vs lumpectomy) and with stopping altogether (OR 3.1 for bilateral mastectomy with reconstruction vs lumpectomy). Chemotherapy receipt (OR 1.3 for missing >1 month; OR 3.9 for stopping altogether) and race (OR 2.0 for missing >1 month; OR 1.7 for stopping altogether; blacks vs whites) also correlated. Those with paid sick leave were less likely to stop working (OR 0.5), as were those with flexible schedules (OR 0.3).

Conclusions: Working patients who received more aggressive treatments were more likely to experience substantial employment disruptions.

Keywords: breast cancer, mastectomy, chemotherapy, employment, job, work

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Introduction

Work is an important source of income, insurance, and social interactions and may be particularly important for individuals with cancer, who may also find that it gives meaning to life, provides a welcome distraction, and improves quality of life.^{1,2} Unfortunately, cancer diagnosis and treatment can disrupt patient employment, particularly during active therapy but also in its aftermath. Treatment plans are burdensome and exact a heavy toll on all aspects of quality of life--including physical functioning and emotional well-being--with protracted recovery times in some cases. Financial toxicity, which can develop in part because of lost income, is an important, yet understudied potential threat to patient and family quality of life after diagnosis.

Prior research regarding the impact of breast cancer diagnosis and treatment on employment experiences has yielded variable results, with some studies suggesting limited impact but others suggesting substantial and lasting effects.³⁻⁷ The divergence of prior study results may be explained in part by differences in study settings and population characteristics, the wide variation in relevant policies and culture in different nations, and changes in treatments offered over time.

Our own prior work has shown that many patients with breast cancer are working for pay at time of diagnosis, that most women with breast cancer who are working for pay before diagnosis lose work time during treatment, and that many stop working altogether.^{5,6} Furthermore, loss of paid work during treatment can result in permanent and undesirable long-term unemployment.⁷ Thus, it is critical that treatments be no more burdensome than necessary and delivered in ways that minimize disruption for patients.

The growing awareness of the burden of cancer treatment is sparking initiatives to reduce it. Use of chemotherapy in early stage breast cancer is increasingly more selective,⁸ and increased attention to symptom control and management may be reducing avoidable morbidity in those who do receive treatment.⁹ By contrast, trends in surgical management may be increasing patient morbidity--for example, the increasing use of bilateral mastectomy, usually with breast reconstruction, in patients with unilateral cancer.¹⁰ But at the same time there are trends toward less extensive surgery--for example, decreased re-excision¹¹ and use of axillary dissection after lumpectomy. Thus, there is a growing dichotomy in surgical management with major potential impact on patient recovery from treatment. It is essential that we understand how this rapidly evolving treatment context may impact employment of women diagnosed with breast cancer.

Policies regarding employment support for patients with cancer have also evolved in light of growing recognition of the importance of these issues,^{12,13} further motivating the need to examine the impact of treatment on employment of patients diagnosed in the United States today. In this transformed landscape of public policy, medical evidence, and treatment options, we sought to document patterns and correlates of missed work in a contemporary population-based sample of women recently diagnosed with breast cancer, with particular focus on associations of employment experiences with primary surgical treatment selected, to inform initiatives to support patients with cancer in their treatment decisions and transitions to survivorship.

Methods

Study Sample and Data Collection

After Institutional Review Board approval, including waiver of signed informed consent, we selected women aged 20-79 years and diagnosed with stages 0-II breast cancer who were reported to the Surveillance Epidemiology and End Results (SEER) registries of Georgia and Los Angeles County. Eligible patients were identified via pathology reports from “definitive” surgical procedures (those intended to remove the tumor with clear margins) in 2014-15. Black, Asian, and Hispanic women were oversampled in Los Angeles using a previously described approach.¹⁴ Questionnaire content was developed using a conceptual framework, research questions, and hypotheses. We developed measures drawing from the literature and our prior research. We assessed content validity, including systematic review by design experts, cognitive pre-testing with patients, and pilot studies in clinic populations.¹⁵

Data Collection

Patient surveys were mailed with a \$20 cash incentive, using a modified Dillman method,¹⁶ including reminders to non-respondents (see Supplementary Material). All materials were in English. We added Spanish-translated materials for all women with surnames suggesting Hispanic ethnicity. Survey responses were merged with SEER data. Median time from diagnosis to survey completion was 7 months.

Measures

As part of a larger questionnaire that evaluated patients' treatment decisions and experiences after diagnosis of breast cancer, we asked patients if they worked for pay before their breast cancer diagnosis and asked their employment status (employed full-time, employed part-time, unemployed and looking for work, temporarily laid off or on sick or other leave, disabled, retired, student, homemaker). We limited our analytic sample for the current study to those who reported working either full-time or part-time prior to diagnosis.

Our primary dependent variable of interest was patient-reported missed work (days missed because of breast cancer or its treatment, with response options of none, less than a week, 7-14 days, 15-30 days, more than a month, and stopped working altogether), which we then categorized for analysis as in our prior work using this measure as having missed 0-30 days, missed >30 days, or stopped working altogether.⁵

Independent variables included patients' clinical, treatment, sociodemographic, and employment-related characteristics. All of these were measured by self-report except for tumor stage, which was taken from SEER registry data. Specifically, the clinical factors we considered were age (measured continuously and categorized as 50 or less, >50 to 65, or >65 to 79), stage (AJCC Stage 0, I, or II), patient-reported comorbidities (presence of one or more medical comorbidities derived from a list pertinent to cancer patients) and overall health status (categorized as excellent, good, fair, or poor using the SF-1). Treatment factors included chemotherapy receipt, radiotherapy receipt, axillary surgery (dichotomized as axillary lymph node dissection versus sentinel node biopsy alone or no surgical nodal intervention) and type of

breast surgery received (categorized as lumpectomy, unilateral mastectomy without reconstruction, unilateral mastectomy with reconstruction, bilateral mastectomy without reconstruction, or bilateral mastectomy with reconstruction). Sociodemographic features included race/ethnicity (grouped as non-Hispanic White, non-Hispanic Black, non-Hispanic Asian, Latina, or other), educational attainment (high school or less, some college or technical school, or college graduate), household income (grouped as <\$40,000, \$40,000-\$89,999, or >=\$90,000), number of people supported by patient's income, and marital status (married or partnered versus not). Employment-related characteristics included self-reported full-time versus part-time status, work hours (grouped as 1-35, 36-44, or 45+), paid sick leave, disability benefits, flexible work schedule, and geographic site (Los Angeles vs. Georgia).

In addition, we inquired, "Since your breast cancer diagnosis, how much money (income) have you lost due to time off from work?" Response options were 0, \$1-\$500, \$501-\$2000, \$2001-\$5000, \$5001-\$10,000, or more than \$10,000.

Statistical Analyses

After limiting the study sample to those who had been working before diagnosis, we described the study sample and its characteristics by amount of missed work (0-30 days, >30 days, or stopped altogether). Next, we constructed a multivariable multinomial logistic regression model of the missed work outcome, using 0-30 days as the reference category. Independent variables included all of the clinical, treatment, sociodemographic and employment-related characteristics listed above, except work hours (to avoid collinearity with self-reported full-time versus part-time status). Multivariable analysis used listwise deletion for all missing data; less than 3% of

cases were excluded due to missing data. Finally, we described the amount of lost income by amount of missed work and compared using the chi-squared test. Using the midpoints of the ranges for the survey questions on household income and income lost due to time off from work, we also estimated the percent of annual income lost. Analyses were conducted using SAS 9.4 and p-values of <0.05 were considered significant.

Survey design and non-response weights were used in all analyses to compensate for the differential probability of selecting patients and survey non-response.¹⁷ All percentages and odds ratios reported herein are weighted and numbers of participants, when provided, are unweighted for clarity. Given low levels of item non-response, complete case methods were used; analyses of data using multiply imputed data (not shown) were consistent with results that we report here.

Results

As shown in Figure 1, of the 3930 women diagnosed in 2014-15 we initially selected for our sample based on rapid case ascertainment (which allows earlier survey administration by reducing the time lag from diagnosis to case identification),¹⁸ 258 were subsequently found to be ineligible due to prior breast cancer diagnosis or stage III-IV disease; residing outside the SEER registry area; or being deceased, too ill or unable to complete a survey in Spanish or English. Of 3672 eligible women remaining, 1170 could not be contacted or did not participate, leaving 2502 respondents (68%). Of these, we considered the 1006 women who reported that they had been working before diagnosis for further analysis in this study.

Table 1 shows the characteristics of the analytic sample, which was racially and ethnically diverse (48% white, 19% black, 20% Latina, and 11% Asian). Most patients (62%) received lumpectomy; 16% had unilateral mastectomy (8% with reconstruction); 23% had bilateral mastectomy (19% with reconstruction). One third (33%) received chemotherapy. The vast majority (84%) reported working full time before diagnosis, but only half (50%) had jobs that allowed for paid sick leave, 39% had disability benefits, and 38% had a flexible work schedule.

Bivariable associations between employment experiences and patient characteristics are provided in Supplementary Table 1. On multivariable analysis, including treatment and clinical factors alone, several factors were significantly correlated with missing more than a month of work or stopping work altogether as compared to missing up to 30 days (Table 2). Those with poorer health (vs. excellent health) were overall less likely ($p < 0.001$) to miss work (OR for stopping work altogether 2.5, 95% CI 1.2-5.1). Chemotherapy receipt also correlated with stopping work (OR 1.3, 95% CI 0.8-2 for missing over one month and OR 3.9, 95% CI 2.6-5.8 for stopping work altogether). Surgical treatment was strongly correlated with missing over one month of work (OR 7.8, 95% CI 4.5-13.4, for bilateral mastectomy with reconstruction, compared to lumpectomy) and with stopping work altogether (OR 3.1, 95% CI 1.6-5.9, for bilateral mastectomy with reconstruction, compared to lumpectomy). Race was correlated with missed work ($p = 0.01$). For blacks versus whites, the OR for missing over one month was 2.0 (95% CI 1.3-3.2) and for stopping work altogether was 1.7 (95% CI 1.1-2.8). Those with paid sick leave were less likely to stop working altogether (OR 0.5, 95% CI 0.3-0.7). Those with flexible work schedule were less likely to stop working altogether (OR 0.3, 95% CI 0.2-0.5) or to miss more than a month of work (OR 0.7, 95% CI 0.5-1). Conversely, women with disability benefits were

more likely to stop working (OR 1.6, 95% CI 1-2.4) or miss over a month of work (OR 2.7, 95% CI 1.8-3.9). Also significant were study site (with patients from Georgia less likely to miss over a month of work, OR 0.6, 95% CI 0.4-0.8), household income (with the highest income group with income \geq \$90,000 having an OR of 0.6, 95% CI 0.3-1, for stopping work), and number supported by family income (with those whose household income supported \geq 4 persons being less likely to stop working altogether, OR 0.4, 95% CI 0.2-0.8). Of note, 7% of patients (13% of those receiving radiotherapy) were still receiving radiotherapy at the time of survey; excluding these patients did not affect the significance of any covariates in the model.

Figure 2 shows adjusted rates of missed work, by surgical treatment received. Patients receiving lumpectomy were far less likely to miss over a month of work or stop working altogether, as compared to women receiving mastectomy.

Those who missed more work also reported losing greater amounts of income due to time off from work since breast cancer diagnosis ($p < 0.001$), as shown in Table 3. Specifically, among those who missed 0-30 days, 74% lost \$0-\$500 and only 6% lost $>$ \$5000. Among those who missed more than 30 days, 40% lost 0-\$500 and 29% lost $>$ \$5000. Among those who stopped working altogether, 17% lost 0-\$500 and 54% lost $>$ \$5000. The median patient reported losing 3.6% of their annual household income due to time off from work, and 19% of patients reported losing 10% or more of their annual household income

Of the women in our analytic sample, all of whom had been employed before diagnosis, 65% reported that their current employment status at time of survey was full-time employment, 15%

reported part-time employment (including 38 of the 844 women who had been working full-time before diagnosis), 3% were unemployed and looking for work, 6% were temporarily laid off or on sick or other leave, 4% were disabled, 4% were retired, 1% were students, and 2% were homemakers.

Discussion

In this large, modern and diverse cohort of patients newly diagnosed with breast cancer, we observed striking variations in rates of missed work by type of surgery received, along with findings consistent with prior research regarding the impact of chemotherapy, sociodemographic factors, and the employment context. These findings are important because never before have women with breast cancer faced such a wide range of choices for surgical management, nor has the dichotomy in surgical treatment options been more dramatic. Some women receive breast conservation, while others receive bilateral mastectomy for exactly the same condition, often also with reconstruction. Understanding the employment effects of different surgical decisions is critically important to the many patients who consider more aggressive surgical treatments than medically necessary to treat their cancer. Surgeons who treat patients with breast cancer can now provide compelling evidence that women who receive mastectomy experience considerably higher risks of missed work than those who receive breast conserving therapy. Moreover, the current data allow quantification of the financial impact of this missed work—data that may be very useful in helping patients understand the full impact of treatment decisions.

Strikingly, the magnitude of risk to employment with more aggressive surgery observed in this study was similar to the risks associated with chemotherapy, which has traditionally been the

major target of efforts to reduce the burden of cancer care. Indeed, most prior studies of immediate treatment impact on breast cancer patients' employment^{19,20} have focused on chemotherapy. Several studies have suggested that patients who received chemotherapy were most likely to experience disruptions in employment²¹ and prolonged absences.²² Although evidence has been more mixed regarding the long-term effects of treatment on employment, with some studies suggesting that breast cancer treatment and particularly adjuvant chemotherapy might not delay or prevent ultimate return to work,^{3,4} there is reason to believe that the adverse effects of chemotherapy on employment may be long lasting. In our group's prior work, adjuvant chemotherapy receipt was associated with long-term job loss among survivors at four years, and many of these women were actively seeking employment, suggesting that this was involuntary.⁷ Women who lacked employment support (sick leave or flexible hours) were most vulnerable. Studies in other settings, including ones with greater employment support, have also documented greater rates of job discontinuation or decreased work time among breast cancer survivors who received chemotherapy.²³ Moreover, recent research has highlighted how certain women, including those with low income, may be particularly vulnerable to the risk of not returning to work in the months and years after treatment.²⁴

As Hassett and colleagues noted in relevant prior work, these findings “reinforce the need to assess the impact of treatments, especially new treatments, on patient-centered outcomes such as employment.” Of note, at the time of most prior studies, rates of mastectomy overall were considerably lower than in the current era, and bilateral mastectomy was rarely used, so it was not evaluated separately from unilateral mastectomy in terms of impact on employment. However, in recent years, in the wake of celebrity disclosures and growing patient interest, rates

of mastectomy overall and particularly in combination with contralateral prophylactic mastectomy have surged: more than one in five patients in the current sample of working patients had bilateral mastectomy. Although some women with early-stage breast cancer are not candidates for breast conservation, most are. Therefore, it is crucial to ensure that patients are fully informed of the risks of treatment, including the potential for impact on employment (a critical component of financial toxicity) to optimize the true goals of shared decision-making. With the growing use of mastectomy, further research is necessary to monitor whether the short-term impact of more aggressive surgery that was observed in the current study will also translate into longer term consequences for these women's employment and well-being.

Prior research has emphasized the importance of workplace accommodations in promoting return to work.^{25,26} In our current study, flexible work arrangements were associated with substantial decreases in missing over 30 days of work or stopping altogether, although disability benefits were found to have the converse association, suggesting that some missed work may reflect the ability of a patient to take the time she needs to recover. Nevertheless, even after accounting for flexibility and other workplace policies, treatments, and particularly more aggressive surgery, had a strong effect that merits note.

Although our study has numerous strengths, including its large and recent sample drawn from population-based registries, it also has limitations that merit consideration. First, as in any observational study, correlation may not imply causation. Still, there is little reason to believe that those who selected more aggressive treatments were predisposed to missing or stopping work, after adjusting for multiple sociodemographic and employment factors. Second, not all

missed work is necessarily concerning; voluntary time off might benefit patients by giving them a chance to cope with diagnosis and treatment. Further research is necessary to determine whether the short-term impact we observed translates into long-term challenges, particularly among the youngest patients, with the greatest years of potential employability, who most often selected the most aggressive surgical options. Third, this study was intended to assess associations between treatment and employment outcomes; therefore, it included only patients diagnosed with breast cancer and not non-cancer patients from the population. Although studies evaluating the employment effects of cancer diagnosis in patients as compared to healthy controls are important, the inclusion of healthy controls was not necessary to study the treatment effects that we sought to evaluate here. Fourth, because patients were surveyed relatively after diagnosis to minimize recall bias, a minority were still completing adjuvant therapy, and the full impact of such treatments (and particularly radiotherapy) might not be appreciated given the timing of survey administration. Fifth, to minimize respondent burden in the context of a larger study evaluating breast cancer treatment decisions, only select employment-related factors were evaluated. We hope to conduct follow-up research with this cohort as they proceed further into the survivorship phase, which will allow us to capture long-term, detailed measures of employment-related constructs of importance to patients. Finally, our study was conducted in two large U.S. areas; the results should be generalized with caution to other U.S. settings and not at all to countries with markedly dissimilar employment support policies or culture.

Implications for clinical care

Our results show that treatment has a profound effect on return to work in the modern era, despite improvements in symptom control and changes in social policy. In addition to policies that further improve employment support, practical actions by clinicians to reduce the overuse of aggressive treatments are of critical importance. In particular, when counseling patients regarding surgical treatment options, the potential impact on employment outcomes and financial impact quantified in this study merits discussion to ensure that patients make choices fully informed regarding potential consequences.

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Figure Legends:

Figure 1: Flow diagram of study participants

Figure 2: Amount of work lost by breast cancer surgical treatment

This figure depicts marginal probabilities of missed work by surgical treatment, derived from a multivariable model adjusting for age, stage, co-morbidities, health status, chemotherapy, radiotherapy, ALND, race, education, marital status, geographic site, employment status, job benefits, income, and household size, weighted to reflect sampling and response rates.

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Tables:

Table 1: Distribution of patients by selected clinical, treatment, sociodemographic, and employment-related characteristics

	N*	% (column)**
Age at Diagnosis		
50 or less	353	35%
51-65	550	55%
66-79	103	10%
Stage		
0	196	20%
I	526	53%
II	263	27%
Any Co-Morbidities		
No	789	78%
Yes	217	22%
Health Status		
Poor	8	1%
Fair	97	10%
Good	371	37%
Very Good	404	41%
Excellent	117	12%
Chemotherapy		
No chemotherapy	658	67%
Chemotherapy	327	33%
Radiotherapy		
No radiotherapy	474	48%
Radiotherapy	518	52%
Surgical Treatment		
Lumpectomy	608	62%
Unilateral mastectomy without reconstruction	77	8%
Unilateral mastectomy with reconstruction	81	8%
Bilateral mastectomy without reconstruction	38	4%
Bilateral mastectomy with reconstruction	184	19%
Axillary Lymph Node Dissection		
No ALND	917	91%
ALND	89	9%
Race		

	N*	% (column)**
Non-Hispanic White	485	48%
Non-Hispanic Black	188	19%
Latina	201	20%
Non-Hispanic Asian	115	11%
Other	17	2%
Education		
High school or less	231	23%
Some college or technical school	298	30%
College graduate or more	460	47%
Marital Status		
Not partnered	367	37%
Married/partnered	625	63%
Site		
Georgia	510	51%
Los Angeles	496	49%
Employment Status		
Part Time	162	16%
Full Time	844	84%
Work Hours/Week		
1-35 hrs/week	213	22%
36-44 hrs/week	562	57%
45+ hrs/week	207	21%
Paid Sick Leave		
No	504	50%
Yes	502	50%
Disability Benefits		
No	613	61%
Yes	393	39%
Flexible Work Schedule		
No	624	62%
Yes	382	38%
Household Income		
<\$40,000	255	28%
\$40,000 - \$89,999	330	36%
\$90,000 +	337	37%
People Supported by Household Income		
1 (Self only)	239	24%
2	369	37%
3	173	18%

	N*	% (column)**
4 Or More	204	21%

*Unweighted number.

**Weighted percentage (to compensate for differential probability of selection and survey non-response).

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Table 2: Adjusted odds ratios for work loss by sociodemographic, clinical, and employment-related factors

	Missed >1 month vs. missed ≤1 month OR [95% CI]	Stopped working vs. missed ≤1 month OR [95% CI]	P value
Age			0.158
50 or less (ref)	1.0	1.0	
51-65	0.7 (0.4, 1)	0.7 (0.4, 1)	
66-79	0.3 (0.1, 0.5)	0.7 (0.4, 1.2)	
Stage			0.174
0 (ref)	1.0	1.0	
I	1.4 (0.9, 2.2)	1.3 (0.8, 2)	
II	1.4 (0.8, 2.5)	1.4 (0.8, 2.4)	
Any Co-Morbidities	0.8 (0.6, 1.3)	0.7 (0.5, 1)	0.285
Health Status			<.001
Poor, Fair	1.3 (0.6, 2.7)	2.5 (1.2, 5.1)	
Good	1.7 (0.9, 3.1)	1.7 (0.9, 3.3)	
Very Good	1.1 (0.6, 1.9)	0.8 (0.4, 1.6)	
Excellent (ref)	1.0	1.0	
Chemotherapy	1.3 (0.8, 2)	3.9 (2.6, 5.8)	<.001
Radiotherapy	1.1 (0.7, 1.7)	1.2 (0.7, 1.8)	0.488
Surgical Treatment			<.001
Lumpectomy (ref)	1.0	1.0	
Unilateral mastectomy without reconstruction	4.0 (2.1, 7.7)	2.5 (1.3, 4.9)	
Unilateral mastectomy with reconstruction	4.0 (2.1, 7.5)	2.3 (1.2, 4.5)	
Bilateral mastectomy without reconstruction	2.6 (1, 7.1)	2.9 (1.3, 6.6)	
Bilateral mastectomy with reconstruction	7.8 (4.5, 13.4)	3.1 (1.6, 5.9)	
Axillary Lymph Node Dissection			0.300
No ALND	1.0	1.0	
ALND	0.5 (0.3, 1.1)	0.8 (0.5, 1.5)	
Race			0.014
Non-Hispanic White (ref)	1.0	1.0	
Non-Hispanic Asian	1.6 (0.9, 2.8)	2.6 (1.4, 4.8)	
Non-Hispanic Black	2 (1.3, 3.2)	1.7 (1.1, 2.8)	
Latina	1.4 (0.9, 2.4)	2.1 (1.2, 3.7)	
Other	0.5 (0.1, 4.5)	2.8 (0.9, 8.8)	
Education			0.846
High school or less (ref)	1.0	1.0	
Some college or technical school	1 (0.6, 1.6)	1.4 (0.9, 2.2)	

	Missed >1 month vs. missed ≤1 month OR [95% CI]	Stopped working vs. missed ≤1 month OR [95% CI]	P value
College graduate	0.9 (0.5, 1.5)	1 (0.6, 1.6)	
Married/partnered	0.9 (0.6, 1.5)	1.5 (0.9, 2.3)	0.546
Georgia (vs. Los Angeles)	0.6 (0.4, 0.8)	0.8 (0.5, 1.2)	0.004
Part Time	0.3 (0.2, 0.5)	1 (0.6, 1.5)	0.252
Paid Sick Leave	1.3 (0.9, 2)	0.5 (0.3, 0.7)	0.002
Disability Benefits	2.7 (1.8, 3.9)	1.6 (1, 2.4)	<.001
Flexible Work Schedule	0.7 (0.5, 1)	0.3 (0.2, 0.5)	<.001
Household Income			0.043
<\$40,000 (ref)	1.0	1.0	
\$40,000 - \$89,999	0.8 (0.5, 1.3)	0.6 (0.4, 0.9)	
\$90,000 +	0.6 (0.4, 1.1)	0.6 (0.3, 1)	
People Supported by Household Income			0.009
Self only (ref)	1.0	1.0	
2	1.2 (0.7, 2)	0.7 (0.4, 1.1)	
3	1.3 (0.7, 2.4)	1.3 (0.7, 2.3)	
4 or more	1.3 (0.7, 2.5)	0.4 (0.2, 0.8)	

Odds ratios produced from a multiple variable logistic regression model. Model incorporates weights to adjust for sampling and response rates. P-value represents Chi-square overall test for association.

Accepted

Table 3: Amount of missed work by income reported lost due to work loss, by amount of work missed

Income Lost Due to Time Off From Work	Zero to 30 days missed		More than 30 days missed		Stopped working	
	n	Column % (weighted)	n	Column % (weighted)	n	Column % (weighted)
\$0	298	66%	121	37%	22	14%
\$1 to \$500	37	8%	10	3%	5	3%
\$501 to \$2,000	54	12%	57	16%	15	8%
\$2,001 to \$5,000	34	8%	55	16%	35	22%
\$5,001 to \$10,000	14	3%	63	18%	33	20%
More than \$10,000	12	3%	35	11%	60	34%

*percentages are weighted to reflect sampling and response rates

Accepted Article

Supplemental Material

Supplementary Table 1: Amount of missed work by selected patient characteristics (bivariable analyses)

	Zero to 30 days missed	More than 30 days missed	Stopped working	P value
Age at Diagnosis				<.001
50 or less	40%	44%	16%	
51-65	53%	31%	16%	
66-79	57%	21%	22%	
Stage				<.001
0	58%	34%	8%	
I	51%	35%	14%	
II	35%	32%	33%	
Any Co-Morbidities				0.352
No	49%	35%	16%	
Yes	50%	30%	20%	
Health Status				<.001
Poor	0%	20%	80%	
Fair	32%	32%	37%	
Good	41%	37%	22%	
Very Good	58%	33%	9%	
Excellent	60%	30%	9%	
Chemotherapy				<.001
No chemotherapy	57%	34%	9%	
Chemotherapy	31%	34%	35%	
Radiotherapy				<.001
No radiotherapy	37%	44%	20%	
Radiotherapy	60%	26%	14%	
Surgical Treatment				<.001
Lumpectomy (ref)	63%	23%	14%	
Unilateral mastectomy without reconstruction	19%	41%	40%	
Unilateral mastectomy with reconstruction	26%	49%	25%	
Bilateral mastectomy without reconstruction	31%	36%	32%	
Bilateral mastectomy with reconstruction	27%	61%	12%	
Axillary Lymph Node Dissection				<.001
No ALND	49%	35%	15%	
ALND	45%	22%	33%	
Race				<.001
Non-Hispanic White	58%	30%	12%	

	Zero to 30 days missed	More than 30 days missed	Stopped working	P value
Non-Hispanic Black	35%	45%	20%	
Latina	37%	36%	27%	
Non-Hispanic Asian	45%	36%	19%	
Other	57%	18%	25%	
Education				<.001
High school or less	39%	34%	27%	
Some college or technical school	50%	33%	18%	
College graduate or more	53%	35%	12%	
Marital Status				0.042
Not partnered	47%	32%	21%	
Married/partnered	50%	35%	15%	
Site				0.115
Georgia	52%	33%	15%	
Los Angeles	46%	35%	19%	
Employment Status				0.039
Part Time	53%	26%	21%	
Full Time	48%	36%	16%	
Work Hours/Week				0.011
1-35 hrs/week	52%	25%	22%	
36-44 hrs/week	48%	37%	14%	
45+ hrs/week	48%	37%	15%	
Paid Sick Leave				<.001
No	47%	28%	25%	
Yes	51%	40%	9%	
Disability Benefits				<.001
No	58%	26%	17%	
Yes	35%	47%	17%	
Flexible Work Schedule				<.001
No	39%	38%	23%	
Yes	65%	28%	7%	
Household Income				<.001
<\$40,000	35%	33%	32%	
\$40,000 - \$89,999	53%	35%	12%	
\$90,000 +	55%	34%	11%	
People Supported by Household Income				<.001
1 (Self only)	50%	28%	21%	
2	54%	32%	14%	
3	40%	35%	25%	

	Zero to 30 days missed	More than 30 days missed	Stopped working	P value
4 Or More	45%	45%	9%	

*percentages are weighted to reflect sampling and response rates

Accepted Article

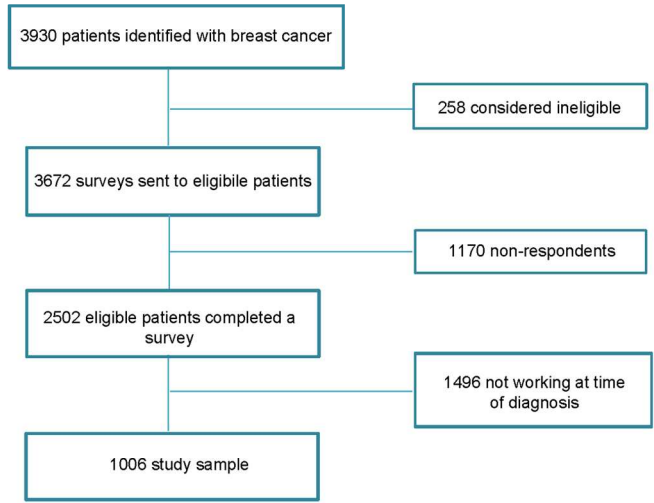


Figure 1: Flow diagram of study participants

171x128mm (300 x 300 DPI)

Accep

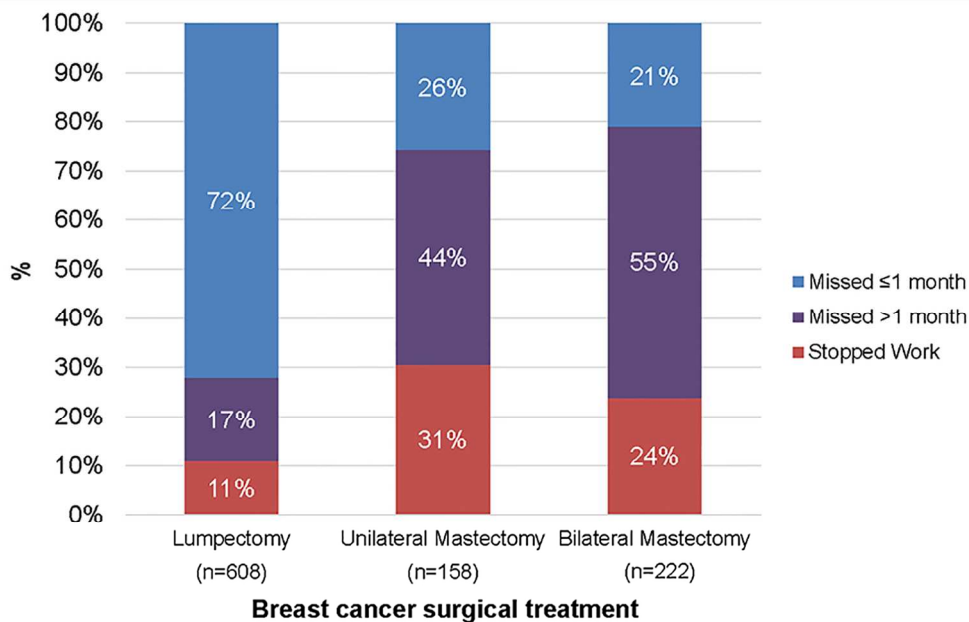


Figure 2: Amount of work lost by breast cancer surgical treatment

This figure depicts marginal probabilities of missed work by surgical treatment, derived from a multivariable model adjusting for age, stage, co-morbidities, health status, chemotherapy, radiotherapy, ALND, race, education, marital status, geographic site, employment status, job benefits, income, and household size, weighted to reflect sampling and response rates.

171x107mm (300 x 300 DPI)

Accep.



Individualized Cancer Care

A study examining women's breast cancer treatment experiences and decision making

Conducted by: Keck School of Medicine at the University of Southern California, Emory University, and the University of Michigan

This study is funded by a grant from the National Cancer Institute and has been approved by the Institutional Review Boards of Emory University, the University of Southern California, and the University of Michigan.

General Instructions

PLEASE READ THESE INSTRUCTIONS CAREFULLY

- Answer each question as best you can. Please do not leave any blank. However, if you feel that you do not wish to answer a question, please write 'skip' next to it and continue on to the next question.

- Put an **x** or fill in the circle ● next to your answer.
Example: Yes or Yes

- Please erase or cross your answer out completely if you want to change your answer.
Example: Yes

- Mark only one response for each question unless other instructions are given, such as "**Mark ALL that apply**".

- Please follow any instructions or arrows that direct you to the next question.
Example: No → **Please go to F9 on the next page.**

- If you mark an answer with a line after it, please write the specific information on the line.
Example: Other (please explain): It was less than one week.

Please be reminded that your responses to this survey are confidential and will not be shared with your doctors.

D

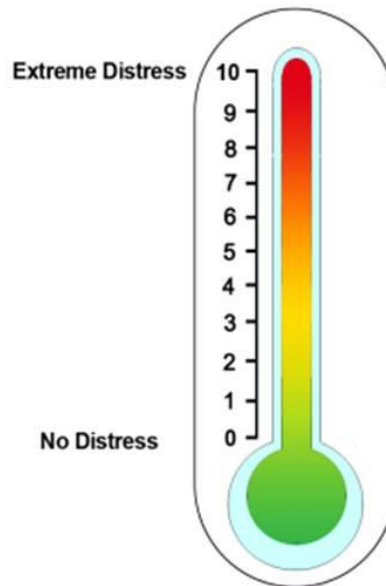
Section A: How Are You Doing?

In general...	Excellent	Very good	Good	Fair	Poor				
A1. Would you say your health is ...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
A2. Would you say your quality of life is ...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
A3. How would you rate your physical health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
A4. How would you rate your mental health, including your mood and your ability to think?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
A5. How would you rate your satisfaction with your social activities and relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
	Excellent	Very good	Good	Fair	Poor				
A6. In general , please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
	Completely	Mostly	Moderately	A little	Not at all				
A7. To what extent are you able to carry out your everyday physical activities, such as walking, climbing stairs, carrying groceries, or moving a chair?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
	Never	Rarely	Sometimes	Often	Always				
A8. In the past 7 days , how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
	None	Mild	Moderate	Severe	Very severe				
A9. How would you rate your fatigue on average ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				
	No pain								Worst imaginable pain
A10. How would you rate your pain on average ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

A11. How are you doing overall?

Please look at the thermometer to the right and write in the number from 0-10 on the line below that best describes how much distress you have been experiencing **in the past 7 days, including today:**

_____ (0-10)



A12. Please tell us whether you have ever been told by a doctor that you had any of the following health conditions:

Yes	No	
<input type="radio"/>	<input type="radio"/>	a. Chronic bronchitis or emphysema
<input type="radio"/>	<input type="radio"/>	b. Heart disease, such as coronary artery disease or congestive heart failure
<input type="radio"/>	<input type="radio"/>	c. Diabetes
<input type="radio"/>	<input type="radio"/>	d. Blood clots in the legs or the lung
<input type="radio"/>	<input type="radio"/>	e. Connective tissue disease, such as lupus or scleroderma
<input type="radio"/>	<input type="radio"/>	f. Stroke
<input type="radio"/>	<input type="radio"/>	g. Depression
<input type="radio"/>	<input type="radio"/>	h. High cholesterol
<input type="radio"/>	<input type="radio"/>	i. High blood pressure or hypertension

Section B: Diagnosis and Testing of Your Cancer

B1. How was a problem with your breast first discovered? **Please mark ONE.**

- The breast cancer was first detected on a routine mammogram
- A doctor or nurse found a lump during a breast exam
- I or my husband/partner found a lump
- I noticed other breast symptoms such as pain, skin change, redness or nipple discharge
- Other (please explain): _____

B2. What was the date when you were first diagnosed with breast cancer? _____ / _____
month year

B3. How did you first find out that you had breast cancer? **Please mark ONE.**

- Radiology doctor who did my biopsy told me
- My primary care doctor told me
- My surgeon called and told me before my first visit with him/her
- My surgeon told me during my first visit with him/her
- A nurse told me before my first visit with a surgeon
- Other (please explain): _____

Next, please tell us about the tests you received to evaluate your breast cancer.

Biopsy

B4. A biopsy is a procedure where tissue or cells are taken from the breast to test for cancer. On which breast did you have a biopsy to diagnose your cancer?

- | | | |
|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Left | Right | Both |

B5. When you first had your biopsy or biopsies that found the cancer, were you told you had cancer in both breasts?

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

B6. One type of biopsy is a needle biopsy. It uses a hollow needle inserted in the breast with local numbing medicine to remove a small amount of tissue from your breast. Sometimes a special imaging machine is used to locate the right tissue to remove.

Before a breast operation, was a needle biopsy used to diagnose your breast cancer?

- Yes No

Breast MRI

Next, we would like to ask you about a **Breast MRI (magnetic resonance imaging test)**. A Breast MRI is a scan in which a patient lies down and is placed inside a machine that uses a powerful magnet to take pictures of the breast. The machine is very noisy. Patients are asked before the test about any metal in the body.

B7. How involved were you in deciding whether or not to have a Breast MRI to evaluate the extent of your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

B8. **After diagnosis**, did you have a Breast MRI to evaluate the extent of your breast cancer?

- Yes →
- No
- Don't know

B8a. Did the results of the Breast MRI change your decision about what type of surgery to have for your breast cancer?

- Yes No Don't know

Other Imaging Tests

B9. How involved were you in deciding whether or not you had other imaging tests – such as CT scans or bone scans – to find out if cancer had spread to other places in your body?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

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.

B10. Did a doctor or other health professional talk with you about having a genetic test for breast cancer risk?

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

B11. Did you have a counseling session with a genetic counseling expert – that is, an appointment where the whole discussion is about genetic risk for breast cancer?

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

B12. How much did you want to have a genetic test to tell you the risk of you or your family developing new cancers in the future?

<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

B13. Has a family member ever had a genetic test to determine if they carry a gene mutation (or change) for breast cancer?

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

B14. Does any member of your family have a gene mutation that increases the risk of breast cancer?

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

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?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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.**

- | | |
|--|--|
| <input type="radio"/> My doctor thought I should | <input type="radio"/> Because of my family history |
| <input type="radio"/> My family wanted me to be tested | <input type="radio"/> To help me decide about my treatment |
| <input type="radio"/> I wanted to get more information about my own health | <input type="radio"/> Other (please explain): _____ |
| <input type="radio"/> I wanted to get more information for my family members | _____ |

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): _____

B19. Which provider ordered your genetic test? **Please mark ONE.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgeon	Medical oncologist	Primary care provider	Genetic counselor	Other (please explain:) _____	Don't know

B20. Which provider(s) discussed the genetic test results with you? **Please mark ALL that apply.**

- Surgeon
- Medical oncologist
- Primary care provider
- Genetic counselor
- Other (please explain): _____
- Don't know
- N/A – I don't have results yet

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

Tumor Tests

Some patients have their cancer tumor sent for additional testing. Examples of this type of test are **Oncotype DX[®]** and **Mammprint/Symphony[®]**.



B22. How involved were you in deciding whether or not to have the Oncotype DX or Mammprint/Symphony test to find out whether you would benefit from chemotherapy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all involved	A little involved	Somewhat involved	Quite involved	Very involved

B23. Was your cancer tumor sent for the Oncotype DX or Mammprint/Symphony test?

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

Please go to C1 at the top of the next page

B24. What were the results of the Oncotype DX or Mammprint test for your tumor?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low risk	Intermediate risk	High risk	I don't remember

B25. How helpful was the Oncotype DX or Mammprint test in making a decision about whether or not to get **chemotherapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

B26. Did the Oncotype DX or Mammprint test change your mind about whether or not to get **chemotherapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made me <u>much less</u> interested in chemotherapy	Made me <u>less</u> interested in chemotherapy	Did not change my mind	Made me <u>more</u> interested in chemotherapy	Made me <u>much more</u> interested in chemotherapy

B27. How helpful was the Oncotype DX or Mammprint test in making a decision about whether or not to get **radiation therapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

B28. Did the Oncotype DX or Mammprint test change your mind about whether or not to get **radiation therapy**?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made me <u>much less</u> interested in radiation therapy	Made me <u>less</u> interested in radiation therapy	Did not change my mind	Made me <u>more</u> interested in radiation therapy	Made me <u>much more</u> interested in radiation therapy

Please continue to C1 on the next page

Section C: Your Treatments

C1. **Before your surgery**, did you consult with any of these providers about your treatment decisions?

Yes No

- | | | |
|-----------------------|-----------------------|--|
| <input type="radio"/> | <input type="radio"/> | a. Radiation oncologist (a doctor who specializes in radiation treatment) |
| <input type="radio"/> | <input type="radio"/> | b. Medical oncologist (a doctor who specializes in chemotherapy) |
| <input type="radio"/> | <input type="radio"/> | c. Plastic surgeon (a doctor who performs breast reconstruction) |
| <input type="radio"/> | <input type="radio"/> | d. Primary care provider (a doctor, physician assistant, or nurse practitioner who sees you for common problems or standard checkups) |
| <input type="radio"/> | <input type="radio"/> | e. Genetic counselor (someone who reviews your family history and explains the purpose and results of genetic tests) |
| <input type="radio"/> | <input type="radio"/> | f. Navigator (often a nurse, someone who helps you with your treatment schedule, test results, or who gives you and your family information about breast cancer) |

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?

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

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

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 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"/>

Please continue to C7 on the next page

C7. Breast cancer sometimes spreads to the lymph nodes under the armpit. Which of the following best describes what was done to the lymph nodes under your armpit? **Please mark ONE.**

- I did not have any lymph nodes removed
- I had a sentinel node biopsy ONLY – where a radioactive material or blue dye was injected into the breast and only one or a few lymph nodes in the armpit were removed
- I had a complete axillary dissection – where all or most of the lymph nodes were removed

A. How were all or most of the lymph nodes removed? **Please mark ONE.**

- I had a needle biopsy before my surgery that showed cancer in the lymph nodes under the armpit, so all of the lymph nodes were taken out later during my surgery
- I had a single operation in which my sentinel nodes were tested and found to have cancer, so all of the lymph nodes were taken out at that time
- I had a single operation in which all of my lymph nodes were removed – no needle biopsy or sentinel node testing was done
- My sentinel nodes were found to have cancer during a first operation, so I had a second, separate operation to remove all of the lymph nodes
- I'm not sure how the lymph nodes were removed

- I don't know

Radiation Therapy

Please answer the following questions even if you did not have radiation therapy

C8. **At the time of your breast cancer diagnosis**, how much time did it or would it have taken you to get from your home to the nearest radiation treatment facility?

- | | | |
|--|--|------------------------------------|
| <input type="radio"/> Less than 15 minutes | <input type="radio"/> 31 to 60 minutes | <input type="radio"/> I don't know |
| <input type="radio"/> 15 to 30 minutes | <input type="radio"/> More than 60 minutes | |

C9. Did any doctor tell you that radiation treatment...

	Yes	No	Don't remember
a. Usually involves daily trips to an outpatient facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Can be completed in 3-4 weeks or less	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer the following questions even if you did not have radiation therapy

In the past, radiation treatment has almost always involved five or six weeks of daily treatment (Mondays-Fridays) to the *whole breast*. Recently, doctors have started to sometimes use shorter courses of treatment.

C10. Did any doctor tell you that a shorter course of radiation (3-4 weeks or less) was an option for you?

Yes No

One kind of short course radiation treatment lasts **3-4 weeks** and treats the **whole breast**. (This is called “hypofractionated whole breast radiation”.)

C11. Did any doctor tell you that this kind of shorter course of radiation (**3-4 weeks**) to the **whole breast**...

	Yes	No	Don't remember
a. Works as well as 5-6 weeks to the whole breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Is still being studied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. May lead to a worse cosmetic result	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Another option for a short course of radiation lasts **1 week or less** and treats only **part of the breast**. (This is called “accelerated partial breast irradiation” or PBI.)

C12. Did any doctor tell you that this kind of short courses of radiation (**1 week or less**) to **part of the breast**...

	Yes	No	Don't remember
a. Works as well as 5-6 weeks to the whole breast	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Is still being studied	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. May lead to a worse cosmetic result	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C13. **When deciding about radiation therapy**, how much did the treatment length (in other words, the number of weeks of visits for radiation) influence your decision?

Not at all A little Somewhat Quite a bit A lot

C14. Did you or are you going to have radiation therapy to treat your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes – I am finished with radiation therapy	Yes – I am still having radiation therapy	Yes – I plan to have radiation therapy but haven't started yet	No

Please go to C14a

Please go to C15 below

C14a. Why didn't you, or don't you, plan to have radiation therapy?
Please mark ALL that apply.

- My doctor(s) did not discuss it with me
- My doctor(s) said I didn't need it
- My doctor(s) left it up to me and I chose not to
- I was worried about side effects or complications
- I was worried about the cost
- It would have been too much of a burden on me or my family
- Other (please explain): _____

Please go to C18 on the next page

C15. How many total weeks of radiation treatments are planned?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1 week	2-4 weeks	5 weeks	6 or more weeks

C16. How was, or will, your radiation treatment be given? **Please mark ALL that apply.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using beams from outside my body	Using a balloon placed inside my breast	Using needles placed into my breast	I don't know how my radiation treatment was, or will be, given

C17. Which of the following areas were, or will be, treated with radiation? **Please mark ALL that apply.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My whole breast	Only the part of the breast where my tumor was	The chest wall, after my mastectomy	The lymph node areas

Please continue to C18 on the next page

Chemotherapy

C18. Chemotherapy is a treatment where medicine is given into a vein to try to kill any cancer cells in the body that may remain after surgery.

Did you or are you going to have chemotherapy to treat your breast cancer?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Yes – I am finished with chemotherapy	Yes – I am still getting chemotherapy	Yes – I plan to get chemotherapy but haven't started yet	No

C19. When did you, or will you, have your first dose of chemotherapy?

- Before I had my surgery (lumpectomy or mastectomy)
- After I had my surgery
- N/A – I will not receive any chemotherapy

Hormonal Therapy

C20. Hormonal therapy helps block estrogen from getting to cancer cells that may remain in the body. Hormonal therapy is sometimes called “anti-estrogen therapy” or “endocrine therapy.” Examples include **tamoxifen**, **anastrozole** or Arimidex, **letrozole** or Femara, and **exemestane** or Aromasin.

Have you or are you going to be taking any of these medications? **Please mark ONE.**

- Yes, I currently take one of these medications
- Yes, I plan to take one of these medications in the future but haven't started yet
- Yes, I took one of these medications before but no longer take it
- No, I am not taking any of these medications right now and I am unsure whether or not I should start
- No, I have no plans to take any of these medications

Side Effects During Treatment

C21. **In the past 7 days**, I have been bothered by side effects of treatment.

<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

C22. During treatment – **including surgery, radiation, and chemotherapy** – please tell us how severe each of these side effects was at its worst.

At its worst, what was the severity of your...

	None	Mild	Moderate	Severe	Very severe
a. Nausea and vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Loose or watery stools or diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Constipation or hard stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Arm swelling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Breast skin irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Feelings of sadness or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C23. Next, we would like to know if you got help from your health care team to deal with any side effects of treatment – even one time. **Please mark ALL that apply on each row.**

	I did not have or seek help for this problem	I called or emailed for help	I discussed it at a routine clinic visit	I went for an <u>unscheduled</u> clinic visit	I went to the emergency room or hospital
a. Nausea and vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Loose or watery stools or diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Constipation or hard stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Arm swelling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Breast skin irritation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Feelings of sadness or anxiety	<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"/>

Chemotherapy decisions

A medical oncologist is a doctor that specializes in discussing and giving chemotherapy and hormonal therapy, when needed, to women with breast cancer.

D15. Did you see a medical oncologist to talk about whether or not to receive chemotherapy?

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

D16. How strongly did the first medical oncologist you consulted recommend chemotherapy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very strongly recommended it	Weakly recommended it	Left it up to me	Weakly recommended <u>against</u> it	Very strongly recommended <u>against</u> it	I did not consult with a medical oncologist

Section E: How You Feel About Your Decisions

Please tell us how you feel about the decisions that were made for your breast cancer treatment. If your doctor did not offer you the test or treatment that is listed, please mark N/A for "Not applicable."

E1. Please rate the amount of information you had when the following decisions were made:

	Not enough		Just right		Too much	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E2. I received enough information about the following topics:

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
a. The effects of breast cancer and treatment on sexual functioning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. The impact of treatment on ability to work inside or outside the home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The effects of having breast cancer on my relationships with family and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The risk of my breast cancer coming back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. How to deal with feelings of anxiety or depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E3. How **satisfied** are you with the decision about...

	Not at all satisfied	A little satisfied	Somewhat satisfied	Quite satisfied	Totally satisfied	N/A
a. Whether or not to have a breast MRI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Whether or not to have your tumor sent for the Oncotype DX test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Whether or not to have a BRCA test to see if you have the gene for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Which type of surgery to have	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Whether or not to have radiation therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Whether or not to have chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section F: Questions about Breast Cancer

Please answer the following questions about the tests and treatments for breast cancer.

F1. Which treatment gives women a better chance of surviving breast cancer?

- Lumpectomy with radiation
- Mastectomy
- There is no difference between these two treatment options
- Don't know

F2. On average, which treatment results in a higher chance of the cancer coming back anywhere in the body after being treated?

- Lumpectomy with radiation
- Mastectomy
- There is no difference between these two treatment options
- Don't know

F3. Does removing the “**other**” **breast** – the breast without cancer – improve survival for ...

	Yes	No	Don't know
a. All women with breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Women with a strong family history of breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Women with a genetic mutation that increases cancer risk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

F4. If any breast cancer cells are found under the arm, do all lymph nodes under the arm need to be removed?

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

F5. Does removing all the lymph nodes under your arm increase the risk of arm swelling?

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

F6. Is it possible that your breast cancer will spread to other parts of your body?

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

Section G: Support from Others

The information below will allow us to better understand how family and friends help breast cancer patients with treatment decisions and will provide us with ideas on how to offer more support in the future.

G1. When decisions were being made about your treatments for your breast cancer, who were the most important people who helped you with those decisions?

Please print the initials of up to 3 people who were involved in your decision making and their relationship to you (e.g. family, friend, other)	How important was this person's opinion in your treatment decision making? Please circle ONE option where 1 is not at all important and 5 is very important.	How satisfied were you with how involved this person was? Please circle ONE option where 1 is not at all satisfied and 5 is very satisfied.	Which treatment decision(s) was this person involved in? Please mark ALL that apply.
EXAMPLE L.W., Daughter	EXAMPLE 1 2 3 4 5 Not at all Important Very Important	EXAMPLE 1 2 3 4 5 Not at all Satisfied Very Satisfied	EXAMPLE <input checked="" type="checkbox"/> Which surgery to have <input type="checkbox"/> Whether or not to have radiation therapy <input checked="" type="checkbox"/> Whether or not to have chemotherapy
1.	1 2 3 4 5	1 2 3 4 5	<input type="checkbox"/> Which surgery to have <input type="checkbox"/> Whether or not to have radiation therapy <input type="checkbox"/> Whether or not to have chemotherapy
2.	1 2 3 4 5	1 2 3 4 5	<input type="checkbox"/> Which surgery to have <input type="checkbox"/> Whether or not to have radiation therapy <input type="checkbox"/> Whether or not to have chemotherapy
3.	1 2 3 4 5	1 2 3 4 5	<input type="checkbox"/> Which surgery to have <input type="checkbox"/> Whether or not to have radiation therapy <input type="checkbox"/> Whether or not to have chemotherapy

G2. Thinking about the family and friends who helped you with your treatment decisions, how often did one of these people...

	Never	Rarely	Sometimes	Often	Very often
a. Attend doctor appointments with you where decisions about your treatment plan were discussed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Take notes for you during a doctor's appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Talk to you about your treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Share information with you from <u>other sources</u> about your treatment options (for example, from the internet or from talking with others)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section H: Communicating with Your Doctors

	None of the time	A little of the time	Some of the time	Quite a bit of the time	All of the time
H1. When it came to getting treatment for breast cancer, I preferred to be told what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H2. When it came to getting treatment for breast cancer, I wanted <u>my doctor</u> to tell me what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H3. I preferred to make my <u>own</u> decisions about my treatments for breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H4. For the next set of questions, please think about the surgeon who was most involved in your surgery.

I feel that my surgeon...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Understood how I saw things with respect to my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Listened to how I would like to handle my breast cancer treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Encouraged me to ask questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H5. How often did your surgeons or their staff help you with referrals to other cancer doctors for treatments such as radiation or chemotherapy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Usually	Always

H6. These next questions are about the medical oncologist who was most involved in the decision about whether or not you had or plan to have chemotherapy.

**If you did not see a medical oncologist,
please go to H7 below**

I feel that my medical oncologist...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Understood how I saw things with respect to my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Listened to how I would like to handle my breast cancer treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Encouraged me to ask questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These next questions are about your primary care provider - the health care provider that you see for general illnesses or routine checkups.

H7. How long have you been seeing your current primary care provider?

<input type="radio"/> Less than 6 months	<input type="radio"/> 6 – 11 months	<input type="radio"/> 1 – 2 years	<input type="radio"/> More than 2 years	<input type="radio"/> I don't currently have a primary care provider
---	--	--------------------------------------	--	---

H8. **Since your breast cancer diagnosis**, how many times have you seen your current primary care provider?

<input type="radio"/> I haven't seen my primary care provider since my diagnosis	<input type="radio"/> 1 time	<input type="radio"/> 2 times	<input type="radio"/> 3 or more times
---	---------------------------------	----------------------------------	--

H9. **In general**, I feel that my current primary care provider...

	Not at all true	A little true	Somewhat true	Quite true	Very true
a. Understands how I see things with respect to my medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Listens to how I would like to handle things regarding my medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Encourages me to ask questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H10. Please read each statement and mark **ONE** response on each row.

	Never	Rarely	Sometimes	Often	Always
a. When you have a new health problem, do you go to your primary care provider before going somewhere else?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Does your primary care provider know what problems are most important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. After going to the specialist or special service for breast cancer, did your primary care provider talk with you about what happened at the visit?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H11. How much did your primary care provider participate in your breast cancer treatment decisions?

<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	A lot

H12. **In the past 6 months**, how often did your primary care provider seem informed and up-to-date about the care you got from your breast cancer doctors?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Always

H13. **After your initial cancer treatment is finished**, which doctor would you prefer to see for each of the following?

	Prefer primary care provider	Prefer cancer doctors	Either one is fine	Prefer to see both
a. Follow-up for breast cancer (mammograms)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Screening for other cancers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. General preventive care such as vaccinations or check-ups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Treatment of my ongoing or future medical problems such as diabetes or heart disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Physical symptoms such as pain, fatigue, or lymphedema	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Emotional problems such as depression or anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Reassuring me about my breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

H14. During your breast cancer care, how satisfied were you with how your doctors worked together?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not at all satisfied	A little satisfied	Somewhat satisfied	Very satisfied	Extremely satisfied

H15. How frequently has one of your cancer doctors (not your primary care provider) done any of the following?

	Never	Rarely	Sometimes	Often	A lot
a. Written a prescription for a problem other than your breast cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Given you a referral to another specialist for something <u>not related to your breast cancer</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Ordered a test for something other than your breast cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section I: Your Thoughts and Feelings

The questions below are important to help us better understand how women like you feel towards the end of treatment and the beginning of the recovery period. Please answer these questions the best way you can.

I1. For the question below, please write in a number from 0% to 100% where...

0% = you think there is absolutely no chance that your breast cancer will come back in the breast or the area around it in the next 10 years, and

100% = you think it is absolutely certain that your breast cancer will come back in the breast or the area around it in the next 10 years

After receiving all the planned treatments, what do you think is the chance that your cancer will come back in the breast or the area around it within 10 years?

_____ % (0 to 100)

I2. After receiving all of the planned treatments, do you consider the chance of your cancer coming back in the breast or the area around it to be:

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Very low	Low	Moderate	High	Very high

13. Next, we would like to ask you for your opinion on the chances of your cancer spreading to other parts of your body. For the question below, please write in a number from 0% to 100% where...

0% = you think there is absolutely no chance that your breast cancer will spread to other parts of your body in the next 10 years, and

100% = you think it is absolutely certain that your breast cancer will spread to other parts of your body in the next 10 years

After receiving all the planned treatments, what do you think is the chance that your cancer will spread to other parts of your body within 10 years?

_____ % (0 to 100)

→ 13a. Why did you pick this number?

14. After receiving all the planned treatments, do you consider the chance of your cancer spreading to other parts of your body to be:

Very low
 Low
 Moderate
 High
 Very high

15. How much did your doctors discuss with you the chance of your cancer coming back?

Not at all
 A little bit
 Somewhat
 Quite a bit
 A lot

16. When your doctors discussed the chance of your cancer coming back, did they use...

Only words
 (For example, "small chance")
 Only numbers
 (For example, "8% chance")
 Both words
 and numbers
 My doctors did not
 discuss the risk with me

17. Compared to other women with similar breast cancer and treatment, how likely do you think it is that your breast cancer will come back?

Much less likely
 Less likely
 About the same
 More likely
 Much more likely

18. **In the past month**, how often have you worried about your cancer coming back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Almost never	Rarely	Sometimes	Often	Almost always

19. **During the past month**, how often has worrying about your cancer coming back...

	Almost never	Rarely	Sometimes	Often	Almost always
a. Made you feel upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Made it difficult for you to carry out your usual daily activities at home or at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Made you feel distant from family and friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

110. When you see your cancer doctors for follow-up care, how often do they ask if you are worried about your breast cancer coming back?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Almost never	Rarely	Sometimes	Often	Almost always

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?

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 | | | |

J10. Has your spouse or partner ever been diagnosed with any type of cancer?

Yes No I don't have a spouse or partner

Section K: Home and Work**Before Your Breast Cancer Diagnosis**

K1. **Before you were diagnosed with breast cancer**, did you work for pay?

Yes No

K2. **Before you were diagnosed with breast cancer**, what was your employment status? **Please mark ALL that apply.**

- | | |
|--|---|
| <input type="radio"/> Employed full-time | <input type="radio"/> Retired |
| <input type="radio"/> Employed part-time | <input type="radio"/> Student |
| <input type="radio"/> Unemployed and looking for work | <input type="radio"/> Homemaker |
| <input type="radio"/> Temporarily laid off or on sick or other leave | <input type="radio"/> Other (please explain): _____ |
| <input type="radio"/> Disabled | _____ |

K3. On average, about how many hours per week did you work **before your diagnosis**? _____ hours per week

K4. **At the time of your breast cancer diagnosis**, which of the following was available to you through your employer? **Please mark ALL that apply.**

- I did not work for pay at the time of my diagnosis with breast cancer
- Paid sick leave
- Disability benefits
- Flexible work schedule
- None of the above
- Other (please explain): _____

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

K6. **At the time of your breast cancer diagnosis**, how many people were supported by the total income for your household, including yourself?

- 1 (just you)
- 2 people
- 3 people
- 4 or more people

During Your Treatment for Breast Cancer

K7. Did you work for pay during **any** of your breast cancer treatment?

- Yes
- No

K8. About how many days of work have you missed because of your breast cancer or its treatment?

- I haven't missed any work
- Less than a week
- 7 – 14 days
- 15 – 30 days
- More than a month
- I stopped working all together

K9. Since your breast cancer diagnosis, how much money (income) have you lost due to time off from work?

- \$0 \$2,001 to \$5,000
 \$1 to \$500 \$5,001 to \$10,000
 \$501 to \$2,000 More than \$10,000

K10. How much have you paid out-of-pocket for medical expenses related to your breast cancer (including co-payments, hospital bills, and medication costs)?

- \$0 \$2,001 to \$5,000
 \$1 to \$500 \$5,001 to \$10,000
 \$501 to \$2,000 More than \$10,000

K11. How much money have you spent over and above your normal budget due to out-of-pocket non-medical expenses related to your breast cancer (such as supplies like wigs, bras, or bandages; travel; child or elder care; and complementary or alternative medicine)?

- \$0 \$2,001 to \$5,000
 \$1 to \$500 \$5,001 to \$10,000
 \$501 to \$2,000 More than \$10,000

K12. Do you currently have debt (for example, unpaid bills, credit card balance, bank loans, or borrowing money from family or friends) from your breast cancer treatment?

- Yes No

K13. Due to the financial impact of having breast cancer...

Yes No

- Yes No a. I had to use savings
 Yes No b. I could not make payments on credit cards or other bills
 Yes No c. I cut down on spending for food
 Yes No d. I had my utilities turned off because the bill was not paid
 Yes No e. I had to move out of my house or apartment because I could not afford to stay there
 Yes No f. Other (please explain): _____

Since your breast cancer diagnosis, are you worse off regarding...

K14. Employment status?

No

Yes → a. How much is this due to your breast cancer and treatment?

Not at all A little Somewhat Quite a bit Very much

K15. Financial status?

No

Yes → a. How much is this due to your breast cancer and treatment?

Not at all A little Somewhat Quite a bit Very much

K16. How much do you worry about current or future financial problems as a result of your breast cancer and treatments?

Not at all

A little

Somewhat

Quite a bit

A lot

K17. How much did you want to talk to your health care providers about the impact of having breast cancer on your employment or finances?

Not at all

A little

Somewhat

Quite a bit

A lot

K18. **During your breast cancer experience**, how much did you discuss the impact of having breast cancer on your employment or finances with each of the following people?

Not at all A little bit Somewhat Quite a bit A lot

a. Cancer doctors

b. Social worker or other professional

c. Primary care doctor

K19. How much did your cancer doctors and their staff help you in dealing with the impact of having breast cancer on your employment or finances?

Not at all

A little

Somewhat

Quite a bit

A lot

Current Status

K20. Are you **currently** working for pay?

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

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

- | | |
|--|---|
| <input type="radio"/> Employed full-time | <input type="radio"/> Retired |
| <input type="radio"/> Employed part-time | <input type="radio"/> Student |
| <input type="radio"/> Unemployed and looking for work | <input type="radio"/> Homemaker |
| <input type="radio"/> Temporarily laid off or on sick or other leave | <input type="radio"/> Other (please explain): _____ |
| <input type="radio"/> Disabled | _____ |

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"/>

K23. In the **last 12 months**, have the costs of your prescription medicine(s) been covered by health insurance?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Completely covered	Mostly covered	Partly covered	Not covered at all	I have not taken any prescription medicine in the past 12 months

Section L: Language and Other Preferences

L1. What language do you primarily speak? **Please mark ONE.**

- English Mandarin Cantonese Korean
 Spanish Vietnamese Japanese Other (please explain): _____

L2. In general, what language(s) do you read and speak?

- | | | | | |
|-----------------------|--|-----------------------|--------------------------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Only English | English better than any other language | Both equally | Another language better than English | Only another language |

L3. What language do you usually speak at home?

- | | | | | |
|-----------------------|--------------------------------------|-----------------------|------------------------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Only English | More English than any other language | Both equally | Another language more than English | Only another language |

L4. In what language do you usually think?

- | | | | | |
|-----------------------|--------------------------------------|-----------------------|------------------------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Only English | More English than any other language | Both equally | Another language more than English | Only another language |

L5. What language do you usually speak with your friends?

- | | | | | |
|-----------------------|--------------------------------------|-----------------------|------------------------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Only English | More English than any other language | Both equally | Another language more than English | Only another language |

L6. Please circle the **ONE** number on each line that best describes your thoughts and feelings.

All things considered, I feel that I...

- a. 1 2 3 4 5 6 7 8 9 10
- Am lucky in life Am unlucky in life

- b. 1 2 3 4 5 6 7 8 9 10
- Almost never worry Almost always worry

- c. 1 2 3 4 5 6 7 8 9 10
- Am very optimistic about life Am very pessimistic about life

L7. How much do you agree with each of the items below?

	Not at all	A little bit	Somewhat	Quite a bit	A lot
a. Through my faith in God, I can stay healthy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I rely on God to keep me in good health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Prayer is the most important thing I do to stay healthy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

L8. How often do you have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Always

L9. How often do you find numerical information to be useful?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Never	Rarely	Sometimes	Often	Very often

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

Section N: Your Doctors

N1. We want to learn from doctors about better ways to communicate with patients and their families about treatment decisions. The information you provide below will help us contact the doctors who treat patients with breast cancer. The doctors may be surveyed about their treatment practices. Importantly, your answers will never be shared with any doctors and your personal information including your name will never be used in any communication.

a. **Surgeon** who performed your first lumpectomy or mastectomy:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

b. **Medical oncologist** who talked to you about or delivered chemotherapy or hormonal therapy:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

c. **Clinic or hospital** where you received most of your chemotherapy:

Name of clinic or hospital: _____

Street address: _____ City: _____

d. **Radiation oncologist** who talked to you about or delivered radiation therapy:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

e. **Plastic surgeon or breast surgeon** who performed your breast reconstruction:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

f. **Primary Care Provider** (or family doctor) who sees you for general illnesses or routine checkups:

Doctor's last name: _____ First name: _____

Name of hospital or clinic: _____

City: _____

Please continue to the next page

Supplemental Material

Supplementary Table 1: Amount of missed work by selected patient characteristics (bivariable analyses)

	Zero to 30 days missed	More than 30 days missed	Stopped working	P value
Age at Diagnosis				<.001
50 or less	40%	44%	16%	
51-65	53%	31%	16%	
66-79	57%	21%	22%	
Stage				<.001
0	58%	34%	8%	
I	51%	35%	14%	
II	35%	32%	33%	
Any Co-Morbidities				0.352
No	49%	35%	16%	
Yes	50%	30%	20%	
Health Status				<.001
Poor	0%	20%	80%	
Fair	32%	32%	37%	
Good	41%	37%	22%	
Very Good	58%	33%	9%	
Excellent	60%	30%	9%	
Chemotherapy				<.001
No chemotherapy	57%	34%	9%	
Chemotherapy	31%	34%	35%	
Radiotherapy				<.001
No radiotherapy	37%	44%	20%	
Radiotherapy	60%	26%	14%	
Surgical Treatment				<.001
Lumpectomy (ref)	63%	23%	14%	
Unilateral mastectomy without reconstruction	19%	41%	40%	
Unilateral mastectomy with reconstruction	26%	49%	25%	
Bilateral mastectomy without reconstruction	31%	36%	32%	
Bilateral mastectomy with reconstruction	27%	61%	12%	
Axillary Lymph Node Dissection				<.001
No ALND	49%	35%	15%	
ALND	45%	22%	33%	
Race				<.001
Non-Hispanic White	58%	30%	12%	

	Zero to 30 days missed	More than 30 days missed	Stopped working	P value
Non-Hispanic Black	35%	45%	20%	
Latina	37%	36%	27%	
Non-Hispanic Asian	45%	36%	19%	
Other	57%	18%	25%	
Education				<.001
High school or less	39%	34%	27%	
Some college or technical school	50%	33%	18%	
College graduate or more	53%	35%	12%	
Marital Status				0.042
Not partnered	47%	32%	21%	
Married/partnered	50%	35%	15%	
Site				0.115
Georgia	52%	33%	15%	
Los Angeles	46%	35%	19%	
Employment Status				0.039
Part Time	53%	26%	21%	
Full Time	48%	36%	16%	
Work Hours/Week				0.011
1-35 hrs/week	52%	25%	22%	
36-44 hrs/week	48%	37%	14%	
45+ hrs/week	48%	37%	15%	
Paid Sick Leave				<.001
No	47%	28%	25%	
Yes	51%	40%	9%	
Disability Benefits				<.001
No	58%	26%	17%	
Yes	35%	47%	17%	
Flexible Work Schedule				<.001
No	39%	38%	23%	
Yes	65%	28%	7%	
Household Income				<.001
<\$40,000	35%	33%	32%	
\$40,000 - \$89,999	53%	35%	12%	
\$90,000 +	55%	34%	11%	
People Supported by Household Income				<.001
1 (Self only)	50%	28%	21%	
2	54%	32%	14%	
3	40%	35%	25%	

	Zero to 30 days missed	More than 30 days missed	Stopped working	P value
4 Or More	45%	45%	9%	

*percentages are weighted to reflect sampling and response rates

Accepted Article